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## ABSTRACT

The report documents services available to persons with autism in West Virginia and recommends types of services needed. A survey is said to have revealed that only 99 persons with autism were served by statewide nonschool programs, in contrast with projections of 1,939 nonschool-age autistic individuals. Background information details the exclusion of autistic persons from medical and social services and cites West Virginia's lack of trained personnel and lack of formal preparation programs in any institution of higher education. A summary of responses to a 20-item questionnaire on existing services is presented, with responses coming from administrators of 34 mental health centers, hospitals and agencies. Recommendations center on diagnostic services, training, parent/family support services (including respite care) and sensitive family counseling, community living alternatives, public awareness, and case management. Appended material includes a summary of other state autism studies and plans. (CL)

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State Plan

The West Virginia Developmental  
Disabilities Planning Council

The West Virginia Department of Health

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July 1, 1982

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Funds to conduct this  
study and prepare the  
state plan were pro-  
vided in part by the  
Federal Developmental  
Disabilities Program.

Acknowledgments

No document of this kind can be the work of a solitary laborer; this Plan is no exception.

Our thanks first to the West Virginia Developmental Disabilities Planning Council members and its director, George Bennett, for having faith in the merit of this proposal. They have been in the DD vineyard when the sun was high and know the weariness and the work it takes to get services for the developmentally disabled.

To Randy Myers, Office of Behavioral Health Services, and R. Kent Bowker of the Developmental Disabilities office, both in the Department of Health, go appreciation for their cooperation and support.

We are indebted to the many dozens of professionals in public and private agencies throughout West Virginia, and quite a few other states, who carefully responded to our requests for information about what was going on for autistic and other handicapped individuals in their area.

We are grateful for the help of Linda Pedretty Rowe, whose recent work on the West Virginia autism education plan lent valuable insight to this one. For helpful suggestions, thanks to William P. Sullivan, Ph.D.,



Marjorie Davis, and Desmond Francik Laux, Ph.D.

Additionally, we are delighted to have been the beneficiary of Julie Ada Sullivan's facility with the language.

Lastly, but specially, we acknowledge the contributions of the members of the Task Force. They spent three days of their lives in meetings at our state capitol so that we could come up with the best recommendations we were capable of. We hope they will feel it was worth the effort.

Ruth Christ Sullivan, Project Director

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\* Listed here are only the committees which would most likely be concerned with the various issues dealing with autistic people.

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## LIST OF ABBREVIATIONS

|          |   |                                                                   |
|----------|---|-------------------------------------------------------------------|
| A        | - | Autism                                                            |
| AA       | - | Associate of Arts degree, conferred by two-year community college |
| A-like   | - | Autistic-like                                                     |
| ASC      | - | Autism Services Center, Huntington, WV                            |
| A spec.  | - | Autism Specialist                                                 |
| BD       | - | Behavior Disorders                                                |
| Cert.    | - | Certified                                                         |
| Cl       | - | Client                                                            |
| CP       | - | Cerebral Palsy                                                    |
| Ch. dev. | - | Child Development                                                 |
| DD       | - | Developmental Disability                                          |
| DDPC     | - | Developmental Disabilities Planning Council                       |
| De       | - | Degree                                                            |
| ED       | - | Emotionally Disturbed                                             |
| EH       | - | Educationally Handicapped                                         |
| MD       | - | Medical Doctor                                                    |
| MR       | - | Mentally Retarded                                                 |
| NSAC     | - | National Society for Autistic Children                            |
| P        | - | Program                                                           |
| PCDC     | - | Potomac Comprehensive Diagnostic Center (Romey)                   |
| Schs.    | - | Schools                                                           |
| Seiz.    | - | Seizures                                                          |
| SW       | - | Social Worker                                                     |
| Sym      | - | Symptoms                                                          |
| Tr       | - | Training                                                          |
| WVSAC    | - | West Virginia Society for Autistic Children                       |



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man's defeat of special handicap"
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Training Center, April 1980
- 5. WVSAC Resolution on the Education of Au-  
tistic and Autistic-like Children,  
November 1981

SECTION TWO

IntroductionNon scholae, sed vitae.

—Latin proverb

(Not for school, but for life.)

Like the rest of us, people with autism and other severely incapacitating disorders need access to lifelong services, including education and training, especially in the formative years. Unlike us, these people who need them so desperately are often systematically denied these services, which in turn further compounds their disability.

Autism is one of the most devastating forms of mental disability. The onset is evident generally within the first 30 months of life. The autistic person appears to suffer primarily from profound central processing disorders. The consequences of this are manifested in the selective impaired development of the sensory-motor, cognitive, social, and language areas. This reduces the ability to understand, communicate, learn, and participate in social relationships. Clara Park (1967) writes of her autistic daughter, then eight:

...of all Elly's inabilities, the hardest to affect was the inability to speak and comprehend (p. 85).

and

Those who pay homage to an ideal of self-sufficiency have never seen the thing itself. The secret smile may be the Buddha's, but it is monstrous seen on a baby's face (p. 90).

and

The severest problem of teaching...is in motivation (p. 274).

Although the cause and cure are yet unknown, effective teaching and other methods of amelioration have been developed which can help autistic persons cope better with life.\* At this time, however, they are typically placed in inappropriate settings which do not allow them to reach their potential, which waste precious years of their lives, and which often lead to regression and severe behavioral problems.

West Virginia has no facilities designed specifically for autistic persons, and at this time has no plans to provide for them and their special needs. This leaves a group of autistic adults many of whom will, in all probability, be subjected unnecessarily to a life of regression and heavy drugs on the back wards of our state institutions—at tremendous cost to the taxpayer— unless we do something.

Doing something is what this Plan is all about.

It began in July 1980 when a proposal was presented to the West Virginia Developmental Disabilities Planning Council (DDPC), pointing to the need for some good hard data on what services are available (and unavailable, as it mostly turns out, to no one's surprise) throughout the state, what parents of autistic children and professionals perceived to be the outstanding needs, and what would be the best and most cost-effective service to develop and provide.

Autism Services Center received a contract from the DDPC and began the yearlong project on July 1, 1981. We surveyed every public and private agency (other than public schools\*\*) that seemed likely to have services for this population, as well as those that

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\* See "Success! Hard-won graduation...", Attachment # 1.

\*\* A survey of autism services in the West Virginia public schools was reported in December 1981 (Sullivan & Rowe).



should or would (if they had funds, staff, space, etc.).

The results of the survey are included in this planning document. No agency we contacted had a plan specifically for autism. Most agencies want more in-service training, especially if they were to serve autistic persons. Some agencies replied with a firm "No" when asked if they thought their program was appropriate for autistic individuals.

The Task Force, made up of parents appointed by the West Virginia Chapter of the National Society for Autistic Children, top-level administrators, and key legislators, met three times: the first time to determine needs, the second to make recommendations, and the third to come to some consensus on who should be accountable for what, and when it should be in place.

We found only 99 persons with autism being served by statewide, nonschool programs. This is in contrast to projected prevalence of 1,939 nonschool-age individuals. (Only 76 out of a projected 986 children were identified in the public schools by the Sullivan & Rowe study of 1981.)

Yet if one goes to a state mental hospital, autism is likely to be represented there 250 times more often than can be expected from numbers in the general population (Sullivan & Rowe, 1981, p. 14).

Four outstanding needs categories under which almost all the others fall are:

—good diagnostic services

- family support
- training
- case management (under this heading come such services as community living alternatives)

A separate category for autism was also identified as imperative. This is discussed at length in the autism education plan (Sullivan & Rowe, 1981, pp. 85-88), which is a companion document to this one. Other issues discussed in that plan are the need for a policy on aversives; the need for standards and certification for persons working in the autism field; and accountability. This last issue is discussed in the recommendations under case manager.

Additionally, from the parents on the Task Force, and from the literature as well as from the authors' experience, there is a clear indication that if autistic persons are to be served well they must be in programs specific to their needs, instead of being placed in those geared primarily to another related handicap (e.g. mental retardation, behavior disorders, learning disabilities, emotionally disturbed). Programs which are successful for one of these groups cannot be expected to be successful for autistic persons.\*

If you are in a hurry and want to get quickly to the heart of this Plan, turn immediately to the Recommendations, which are only three pages long. If you want to understand how the recommendations came to be, and why the Task Force and Project directors thought they were important, spend a few minutes reading the Discussion of

---

\* For an excellent example of a model program for severely handicapped mentally retarded children which was not successful for an autistic child, see p.74.

the Recommendations.

This plan, we believe, has met the criteria for good government set by the League of Women Voters (National Voter, 1982):

- competent personnel with clear responsibilities
- coordination among agencies and levels of government
- adequate financing
- effective enforcement, and
- well-defined channels for citizen input and review (p. 1).

If we can put these into practice, perhaps, at last, we can begin to open doors for West Virginians with autism.

Definition

For the purposes of this Plan, the definition of autism as adopted by the National Society for Autistic Children in 1977 (see Appendix 1) will be used throughout. It is closely followed by the Diagnostic and Statistical Manual of Mental Disorders (DSM III) published by the American Psychiatric Association.

This definition is sufficiently broad to include students who are autistic-like, and who, for educational and most other services, generally benefit more from a program tailored for the unusual learning styles and behavior of autism than from programs for other developmentally disabled.

### How This Plan Was Developed

Rather than proceed with a piecemeal, haphazard solution to the statewide problems of autism, we organized a Task Force of the three major groups which would be involved in any autism plan—the parents, representatives from the key agencies, and representatives from key committees of both houses of the legislature (see Task Force membership list, p. iii). These three groups, working together, would, we believed, save precious time for all parties. Parents would have the opportunity to express their perception of needs, solutions, and priorities directly to the very persons (agency representatives and legislators) whose job it is to respond. The agency representatives and legislators in turn would be able to present their views on the reasonableness and cost-effectiveness of the consumers' recommendations and perhaps suggest new ones. The legislators would be present to help develop ideas for legislation that might be needed and to discuss the feasibility of the Task Force's proposals.

It was hoped that these three major groups could reach agreement on what needs to be done, as well as how, who should do it, and when.

And that is what happened. The recommendations for this plan (see pp. 47 - 49 ) were unanimously adopted. They were the results of three day-long Task Force meetings— in October 1981, January 1982, and March 1982.



Projections: How Many West Virginians  
with Autism?

Methodologically rigorous epidemiological studies of autism (Sullivan, 1976), beginning in the 1960's are surprisingly corroborative, each arriving at approximately 4.6:10,000. The National Society for Autistic Children (U.S.) uses 5:10,000. This was for classic autism.

In 1979, a report of a new study in the United Kingdom revealed at least 12:10,000 and, in some geographic areas, 20:10,000, using a broader definition which would include autistic-like (Wing, 1979). Dr. Wing pointed out that identification methods in medical research should differ from those used for education and social service planning.

The National Society for Autistic Children now uses the prevalence rate of 15:10,000 (NSAC Advocate, 1980, p.6).

Based on these figures the projections for West Virginia are as follows: (using data from the Bureau of the Census, May 1981):

| <u>AGES</u> | <u>WV Population</u> | <u>AUTISTIC<br/>0.04%</u> | <u>AUTISTIC-LIKE<br/>0.15%</u> |
|-------------|----------------------|---------------------------|--------------------------------|
| All         | 1,949,644            | 780                       | 2,925                          |
| under 5     | 145,583              | 58                        | 218                            |
| 5 to 9      | 152,802              | 61                        | 229                            |
| 10 to 14    | 157,489              | 63                        | 236                            |
| 15 to 19    | 174,204              | 70                        | 261                            |
| 20 to 24    | 172,688              | 69                        | 259                            |
| 25 to 29    | 160,954              | 64                        | 241                            |
| 30 to 34    | 144,649              | 58                        | 217                            |
| 35 to 39    | 109,878              | 44                        | 165                            |
| 40 to 44    | 97,541               | 39                        | 146                            |
| 45 to 49    | 93,307               | 37                        | 140                            |
| 50 to 54    | 104,805              | 42                        | 157                            |

| <u>AGES</u> | <u>WV Population</u> | <u>AUTISTIC</u><br><u>0.04%</u> | <u>AUTISTIC-LIKE</u><br><u>0.15%</u> |
|-------------|----------------------|---------------------------------|--------------------------------------|
| 55 to 59    | 105,219              | 42                              | 158                                  |
| 60 to 64    | 92,657               | 37                              | 139                                  |
| 65 and over | 237,868              | 95                              | 357                                  |

(calculations have been rounded off to the nearest whole numbers)

In the school-age population (ages 5 to 24, roughly) we can project that there are 263 autistic and 986 autistic/autistic-like West Virginia residents. Thus there are some 517 autistic people and a total of 1939 autistic and autistic-like people in the state who are ineligible, by virtue of age, for public school education services.

Autism and the DD Act: A Historical Note

There is a long, painful history of exclusion— not segregation, but almost total exclusion— of autistic individuals from every known medical and social service, especially in public agencies. In addition, there are probably no parents who have been more maligned by the very professionals thought most likely to help than parents with autistic children. The mental health literature until recently (even into the early 1970s) was filled with nonscientific and pseudoscientific pronouncements about "cold parents" and "refrigerator mothers" who produced autistic children.

Largely because this theory was for a time widely accepted, autism was deliberately not included in the 1970 Developmental Disabilities Act (Sullivan, 1979). Inclusion depended on a disorder's being "neurological." Under pressure from the National Society for Autistic Children (NSAC) to include autism in the DD definition, the National Advisory Council on DD, at one of its meetings, discussed the issue and proclaimed, on the authority of one of its members— a neurologist— that autism was psychogenic (!) and therefore not eligible for funds under the DD Act. This dictum, writes Mary Akerley (1979)

...had the happy effect of enraging and therefore further energizing the NSAC advocates, who had fought that battle long and hard on other fronts (p. 226).

The ~~Secretary~~ of Health, Education and Welfare (HEW— now Health and Human Services) was inundated with evidence from a wide range of professionals in the field that autism has a physiological base. The rest is history. In 1975 autism was included in the definition as

another neurological disability, making that law historically significant for autism.\* A Parents Speak column points out (Sullivan, 1979):

So important is this law to the field of autism that probably most... parents (of autistic children) and (autism) professionals have been affected in some way by the flow of funds it generated for autistic citizens. Those brief 3½ years since its passage have seen the establishment of many services for our children, often for the first time, usually where none existed before (p. 221).

Once autism was clearly identified as a disorder to be served under the DD Act, parents of autistic children began to be appointed to state DD Planning Councils, and funds began to be assigned to autism projects. A great deal of credit for the unprecedented (often first-ever) attention to this disorder since the mid-seventies can be given to the inclusion of autism in the DD definition.

In West Virginia, autism had no representation on the DDPC until 1979. Since 1976, however, the DDPC has financially contributed to annual conferences (and some spring meetings) of the West Virginia chapter of NSAC. These have been the major autism training activities for the state— for parents, professionals, and students. In July 1981 the Council made its first relatively substantial commitment to autism with the funding for this plan. (See Attachment #2.)

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\* P.L. 94-142, the Education for All Handicapped bill, was passed in 1975, too, and it is extremely important for all handicapped. But autism was not given a special category in it until 1978.



Autism in West Virginia: Brief Background

The severe and profound disability of autism combines a low-incidence handicap with a puzzling and still little-understood disorder which leaves its victims and their families mostly unserved or pitifully underserved.

Though no other persons with DD have a better fit under the DD definition (both the old categorical one and the newer functional one), those with autism remain mostly untouched by the federal DD funds which began coming into West Virginia in 1970.\* Traditional programs for the DD population often, even usually, do not accept autistic persons. If they do, it is ordinarily on a short-term basis, often terminated the first time the staff witnesses an autistic tantrum, or when they become frustrated at their lack of skill in dealing with the autistic person's highly unusual handicap, or when the supervisor realizes the child/adult is taking up too much staff time, therefore running up the cost of the program. At this point the parents/guardians are very often asked to remove their child because "he doesn't fit the program."

The pervasive lack of trained,\*\* experienced personnel in the various agencies (e.g. Health, Welfare, Education, Voca-

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\* See attachment # for list of expenditures for autism by the WV DD Planning Council.

\*\* In the last few years, the West Virginia Department of Education sent approximately 12 teachers for out-of-state training. In early 1982, Colin Anderson Center sent three professional staff. Except for an occasional trained teacher or other professional who moves into the state, these few make up the West Virginia cadre of autism professionals.



tional Rehabilitation) makes appropriate services for autistic persons almost nonexistent.\* Even if agencies had all the necessary funding for case management, or community living, or child development services, or education, if they do not develop a staff with appropriate skills to help persons with autism, that funding will not do much to change the bleak situation for this population of "hard-core" handicapped.

West Virginia has no institution of higher education formally preparing professionals in the field of autism.\*\* Our survey of state programs, agencies, and facilities found very few who indicated staff with any special qualifications in autism. Colin Anderson has admitted (sometimes by court order) individuals with an autism label, but, like every agency responding to our questionnaire (97%), it has no specific program suited to autistic individuals. Except for the education system, which is mandated to serve all handicaps, including autism, there is an almost shut-out of these persons from the health and social services systems in West Virginia.

Various approaches to solving these problems have been tried in a few states. Almost always, it is a consumer-initiated effort, sometimes pushing open doors to agencies who were not prepared to deliver what the consumer group was demanding. Problems develop between the two parties. Services are delayed or never developed. Sometimes litigation follows.

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\* There are a few public school classes for autistic students scattered throughout West Virginia, some staffed by the above-mentioned teachers.

\*\* Marshall University has since 1980 conducted a week-long summer program for about 12 autistic children.

**SECTION THREE**

SURVEY OF EXISTING SERVICES FOR AUTISTIC PEOPLE  
IN WEST VIRGINIA

Criteria for Autistic and Autistic-like Label

In order to be as clear as possible, given the survey process, about the kind of individual we are concerned with, we included with our questionnaire "A Short Definition of Autism," published by NSAC (1977), and a brief description by Wing (1973). (See Appendix 1 and 2.)

Survey Instrument

A 20-item questionnaire (See Appendix 3) was compiled to elicit information about existing services. It was used for both telephone and mail surveys.

Time Frame

Between the months of September 1981 and February 1982, community mental health centers, hospitals, clinics, social services agencies, group homes, and a home for the aged in the State of West Virginia were contacted by phone or by mail to determine existing services for autistic citizens in this state. The telephone interviews were conducted in September and October to get a feel for reactions to our survey. Most questionnaires sent by mail were answered promptly. In November we sent a second notice to those who had failed to respond to the questionnaire. In January we sent a third reminder to a few remaining directors and supervisors.

Centers/Hospitals/Agencies Surveyed

As our source for existing community mental health services, we used

the booklet Community Behavioral Health Programs of West Virginia published by the WV Department of Health, and their directory of 1982 for state hospitals and centers, entitled Departmental Directory.

Nineteen of the preliminary interviews were conducted by telephone with directors, administrators, and supervisors. We sent the same questionnaire to 37 remaining other mental health centers, hospitals, and agencies.

#### Follow-up

If directors or supervisors said in their responses that clients came weekly or monthly to their facility, we wrote a follow-up letter to have them describe in specific terms what kind of service they provide (e.g. self-help skills, behavior assessment, etc.).

#### Responses

The response to the 20-item questionnaire was impressive: 34 of 35 replied, making the return rate 97%. Two letters were returned because the centers were no longer in existence. Altogether, we worked with 53 interviews, 19 by phone and 34 by mail: 21 mental health centers, 21 hospitals/clinics, 8 agencies, 2 homes, and one school for the deaf and blind.

#### Autistic and Autistic-like Identified by This Survey

The response to question # 3 concerning identification of autistic and autistic-like people reveals that 69 were identified as autistic and approximately 30 as autistic-like.

A December 1981 (Sullivan & Rowe, 1981) survey of school-age autistic children found 8 autistic individuals and 46 autistic-like individuals, and 22 in a combined category, served in the WV public school system. One can infer, then, that facilities working with pre- and post-school-age clients have identified a considerably higher number (99) than public schools in West Virginia (76).



Summary of Responses

QUESTION 1: "Do you currently serve autistic or autistic-like people in your agency/institution?"

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "NO"          | 28            | 52.8%          |
| "YES"         | 25            | 47.2%          |

Comments were as follows:

NO

"Our hospital has no contact with autistic people."

"None diagnosed as such."

"Our hospital is only for acute patients."

"We refer them to Psychiatric Department of our hospital."

"No active cases."

"At present time Center only serves physically disabled; will include other handicaps possibly at later date."

YES

"Would rather not serve autistic clients because our milieu doesn't fit autistic clients' needs."

"We see some autistic-like patients in Behavior Clinic twice monthly."

"We see them to confirm diagnosis."

"We do diagnostic work-up."

"Children 0-5 with autistic tendencies served through our Developmental Counseling Program."

"We serve retarded children with autistic-like symptoms."

"We serve two autistic-like people with multiple handicaps."

"We see very few."

"One who has not been diagnosed."

"Some autistic-like."

"Minimal."

"We serve 5 with autistic tendencies."

"We see them for audiological care; e.g., brainstem test."

"Only for evaluation services; 1 client might enter work-adjustment program."

"WV Rehabilitation Center, branch offices and district offices - state-wide - (can) serve them."

"Most with MR or CP."



QUESTION 2: "If none now, have you had any before?"

| <u>Answer</u>             | <u>Number</u> | <u>Percent</u> |
|---------------------------|---------------|----------------|
| "No"                      | 11            | 20.8%          |
| "Yes"                     | 13            | 24.5%          |
| "N.A." or<br>"Don't know" | 6             | 11.3%          |
| No Answer                 | 23            | 43.4%          |

QUESTION 3: "How many have you identified?"

Eight had not identified any. Answers varied from 0-23. Altogether, 69 had been identified as autistic and approximately 30 as autistic-like.

Comments were as follows:

"18 to 23 MRs with autistic characteristics."

"8 since 1977."

"A few with autistic behavior."

"2 autistic-like with multiple handicaps."

"Approximately 6 during first 6 years."

"No collected data; many have more than only one diagnosis - often conflicting diagnosis."

"A couple of pre-schoolers have not been diagnosed."

"Current reporting system does not identify autism, so statistics are not available."

QUESTION 4: "How many have been formally diagnosed? By whom?"

Fourteen responded with 0; 3 with "Unknown", and 2 with "Not applicable."

The majority of the persons listed as having diagnosed the autistic clients were physicians in private practice, psychologists, psychiatrists, educators, and medical doctors in behavioral clinics. One was said to have been diagnosed by the Judevine Center in St. Louis, Missouri.

QUESTION 5: "How are autistic clients referred to you?"

Predominant responses were as follows, in priority listing:

"Community Mental Health Centers."

"Physicians in private practice."

"Departments of Welfare, Health, and Education."

"Agencies."

"Parents, families."

"State institutions."  
 "Clinics, psychologists."  
 "Social Security Administration."  
 "Autism Services Center, Huntington."  
 "Developmental disabilities workers."

QUESTION 6: "Where do you refer them if you cannot serve them?"

Seven responded with "Ruth Sullivan at Autism Services Center in Huntington." (Autism Hotline)

Other responses were as follows (if responses overlapped, similar response is not quoted):

"Back to Community Mental Health Centers, Departments of Health and Education and county schools."  
 "Variety of programs; depends on need."  
 "Webster MHC."  
 "Elkhorn MHC."  
 "If mainly retarded - encouraged to participate in educational and recreational programs."  
 "Marshall University."  
 "Department of Health."  
 "Shawnee Hills."  
 "Back to public schools or Community Mental Health Centers."  
 "To Dr. Kelley in Psychiatric Department at WVU MC Morgantown."  
 "The National Society for Autistic Children - WV chapter." (WVSAC)  
 "Colin Anderson Home-Life Program."  
 "Colin Anderson for short-term placement."  
 "Greenbrier Center if young; Weston if adult."  
 "WV School for the Deaf and Blind, schools, Potomac Comprehensive Diagnostic Center."  
 "Kanahwa Board of Education."  
 "State Department of Institutions."  
 "Green Acres, Prestera MHC, Cabell County School Board, Region III Child Development Services."  
 "Education agencies, CMHC."  
 "Schools with self-contained classrooms."  
 "At this time, we have always serviced any child in need of services."

QUESTION 7: "Do you have a specific program for autistic persons?  
What kind of program? (e.g., education, psychotherapy,  
group home) "

Not a single response was "Yes." All 53 questionnaires indicate they have no specific program for autistic persons.

Several people made comments:

"As yet no, though a recent state agency-level decision has been made to develop a specific education/habilitation/residency program."

"No separate program - program in education and training."

"No treatment program."

"Only diagnostic format."

"Usually for diagnostics only."

"Counseling program for individuals and families."

"New Children's Program."

"One attends an activities program, one MR program - twice a week."  
(Same response by two different MHCs).

"Autistic clients can participate in work-adjustment program and dial-a-ride program."

"Group Home Program."

"Ancillary services."

"Service all types of disabilities in our infant and pre-school programs."

QUESTION 8: "Do the autistic people come to your institution/agency for service? How often? Daily? Weekly? Monthly?"

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "No"          | 13            | 24.5%          |
| "Yes"         | 14            | 26.4%          |
| No Answer     | 26            | 49.1%          |

Comments were as follows:

"We have a residential program."

"For the two who come: behavior modification program--social and self-help skills."

"Short stay helped mother."

"Those with referral from court or MHC come to our institution."

"Sporadic, not formal."

"Behavior clinic twice a month."

"None now."

"Home-based services weekly."

"No programs."

"Autistic-like people come daily."

"Usually for diagnostics only."

"Monthly visits."

"One client comes daily."

"Training daily; testing annually."

"Twice a week."

"One child comes once a month for social services. We served three in three years; e.g., with hearing aids."

"Coordination with school system for speech therapy."

"Could be daily in WV Rehabilitation Center in Institute."

"One in 6 years."

"Daily for work adjustment training--1 autistic client out of 110 clients."

"Daily visits to Community Mental Health Centers by clients in 5 different centers."

QUESTION 9: "What qualifications to work with autistic persons do your teachers and other staff have?"

Very few indicated any special qualification in the field of autism. Many indicate backgrounds in nursing, speech, medical and social work, counseling, or general psychology and special education backgrounds. Ten answered with "None."

Comments were as follows:

"Professional staff: College-trained in special education, psychology--including developmental and abnormal--and special training such as in speech and language for those appropriate, all with emphasis on behavioral procedures in addition to workshops, and locally provided training, and in-service on a continuous basis. Paraprofessional staff: Induction and continuing in-service training in human growth and development and behavior modification."

"University training; in-service training."

"No trained staff in education."

"No formal training or experience in autism."

"One psychologist has had training in autism."

"Staff is certified; registered music therapist in private practice; BD and LD certification."



"Medical and nursing staff."

"Trained at medical center and what is seen in clinic in regard to autism."

"Medical professionals; psychologist is not Judevine-trained."

"No specific qualifications; several staff members have attended workshops on services & programs for the autistic."

"Minimal."

"Degrees and training as psychologists, social workers, and medical back up."

"M.Ed. in Special Education; B.A. in Psychology."

"BD, MR certification."

"No formal program available."

"Out-of-state experience: one taught in residential setting; 1 worked with autistic child and family in Mental Health Center."

"Limited qualifications; staff has worked with MR adults for 5 years."

"Minimal in-service training & workshops; academic training of professional staff."

"Teachers in Spec. Ed. could diagnose condition."

"Psychologists & social workers have had one or two graduate classes in which they were exposed to autism. No one has extensive training."

"B.A. degrees in helping professions area."

"No special qualifications other than license for RNs, PTs, OTs, MDs--certification in their field."

"MR counselors; B.A. in psychology."

"AA - Child Dev.; Special Ed.; M.A. in Special Ed.: psychiatrist and physical therapist."

"Certified speech/language pathologist; psychologist; special ed. teacher."

"Experience in (agency's) specific curriculum for autistic children and supervision by a board-certified child psychiatrist."

QUESTION 10: "How many teachers/staff have formal training in autism? Where did they get training? What kind of training? (Specify the degree, certificate, etc.)."

Thirty-one answered with "None"; i.e., no specific training in autism. In other words, 58% have no formal background in autism.

Other comments were as follows:

"Medical School."

"One staff member has B.A. in Home Economics with some graduate hours in MR."



"General training in special education with graduate program."

"Attended state seminars by WV Autistic Society." (WVSAC)

"Shawnee Hills training."

"One staff member had training in Hope Program."

"Two - precise figure unknown."

QUESTION 11: "In addition to training, what kind of experience have teachers/staff had? Where was experience received? Extent of experience? Was it supervised? With what age group?"

Eleven answered with "None." Many indicated that their experience with autism was very limited. Six answered "N.A."

Other comments were as follows:

"Supervised training: early childhood to adult."

"Varies widely."

"Educational and recreational services."

"One nursing staff member has an autistic child of her own."

"Training with ages 4-9 for one year."

"Pediatric residents during out-patient residency go to Shawnee Hills."\*

"Only in their clinic."

"Limited, if any."

"Informal training in homes for ED children in Iowa - ages 5-7 and 10-11."

"On the job."

"Out-of-state experience in MHC setting."

"All members have worked with the program since the beginning."

"University of Southern Missouri; 1 staff member experience with elementary school age children: consultation, observation, supervision."

"On their jobs; limited experience with pre-school and post-school supervision at previous jobs."

"No formal experience or program in autism."

"WV Rehabilitation Center - limited experience; no supervision; 16 and above."

"Unknown."

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\*An MR facility with no specific program for autistic clients.

"All staff members at least 2-6 years in group homes."

"On the job experience at Northern Panhandle MHC under supervision of MD (ages 2-10)."

"Practical experience with our 1 autistic client."

"Various workshops and in-service--dealing with various needs of young handicapped children."

"Seventy-five percent are behavior-trained."

QUESTION 12: "How many teachers/staff have not had formal training in autism--refer only to those who work with with autistic people? Do they have related training? (Specify degree, source, etc.)"

The answers indicate that of those working with autistic people, few have had formal training in autism. Some have college degrees in special education and were exposed to some information on autism in their classes. Many have had related training as psychologists, audiologists, social workers, nurses, speech pathologists, etc. Most are certified in their respective fields and have appropriate training in their fields but not in autism per se. Two have had residential training in which they encountered some autistic or autistic-like people.

| <u>Answer</u>                 | <u>Number</u> | <u>Percent</u> |
|-------------------------------|---------------|----------------|
| "None" (with formal training) | 9             | 17.0%          |
| "Related training"            | 16            | 30.2%          |
| "N.A."                        | 7             | 13.2%          |
| "Unknown"                     | 1             | 1.8%           |
| No Answer                     | 20            | 37.7%          |

Comments were as follows: (Some give the number of their staff who work with autistic people but have no formal training.)

"Fourteen staff members in the DD Program and 10 in the Children's Program who might work with autistic people."

"Twenty-nine have not had formal training in autism. Psychologists have had related training."

"One has not had formal training."

"Ten to twelve - some have had special education training. Most are certified in respective fields; e.g., social workers and nurses."

"Twenty-one have had practical training but no formal training."

"No specific staff designated to work with autistic children only."

"All three have related training."

"All have received in-service training."

"Two have had related training."

"Special education degrees - some exposure to autism at Radford University in Virginia."

"Certified personnel in special education, audiology, speech and language, licensed psychologists (early childhood to adult experience)."

"Varies widely."

"Some training with autistic symptoms - secondary to severe delay."

"Psychology and social work."

"One licensed clinical psychologist, one certified speech pathologist."

QUESTION 13: "What kind of experience have non-trained teachers/staff had? Where was experience received? Was it supervised? Extent of experience? With what age group?"

Very few people answered this question in detail. Many ignored it altogether. The responses indicate that only a few have had hands-on experience with autism under supervision. On-the-job-experience was reported in four cases. Related job experience, educational training, and in-service training were other responses given. Several people indicated their staff has no experience with autistic people.

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "None"        | 5             | 9.4%           |
| "Unknown"     | 1             | 1.9%           |
| "N.A."        | 9             | 17.0%          |
| No Answer     | 38            | 71.7%          |

Comments were as follows:

"Supervised experience; early childhood to adult."

"Limited experience at Rehabilitation Center: no supervision - ages 16 and above."

"Varies widely."

"All have received in-service training."

"On the job training; limited experience; pre-school to post-school supervised."

"Experience only through contacts with families."

"All staff at least 2-6 years training in group homes."

"Practical training."

QUESTION 14: "How are autistic students/clients/patients classified?  
(e.g., behavior disorders, emotionally disturbed)."

Eight responded with "classified as autistic"; four answered: "autistic-like behavior"; four "developmentally disabled." Six answered "N.A."; four "not classified"; two "BD" and two "ED".

Comments were as follows:

"Autistic--questionable autism."  
 "Autistic--DSM III criteria."\*  
 "Varies widely, depending on clinician who does assessment."  
 "Data not available."  
 "ED."  
 "Developmentally disabled."  
 "Developmentally delayed with autistic tendencies or formal autism diagnosis."  
 "Multi-handicapped."  
 "Generally within behavior disorder."  
 "Not classified except as developmentally disabled."  
 "M.P." (sic)  
 "Primarily profoundly retarded."  
 "Autistic; ED."  
 "Severely disabled."  
 "Display autistic tendencies in addition to physical handicaps."  
 "One child hearing-impaired with autistic symptoms."  
 "Mental, emotional, mental retardation, psycho-neurotic."  
 "MR or C.P."  
 "No special classification."  
 "BD."  
 "BD--two have emotional disturbance."  
 "Pervasive developmental disorder."  
 "Not classified."

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\*DSM III is the abbreviation for Diagnostic and Statistical Manual, Third Edition, which is a publication of the American Psychiatric Association. It is a standard listing of psychiatric disorders, and is commonly used for identifying which treatment costs will be covered by insurance companies.



QUESTION 15: "Is the severity of the disability a criterion for admission or discharge?"

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "No"          | 15            | 28.3%          |
| "Yes"         | 18            | 34.0%          |
| "N.A."        | 4             | 7.5%           |
| No answer     | 16            | 30.2%          |

In several instances the answers were "No" for admission but "Yes" for discharge.

Comments were as follows:

"Yes for admission, no for discharge."

"Yes, now, but not in the past."

"No for admission, yes for discharge."

"No, when only diagnostic."

"Yes - our group home meets some needs; our MHC only sees clients on out-patient basis."

"Yes at the 0-5 range; significant delay and parent consent must be present."

"Yes for discharge, no for intake."

"Yes, cannot deal with severely disabled in unstructured environment."

"Severely disabled must benefit from services for independent living."

"At WV Rehabilitation Center each applicant receives individual consideration."

"Degree of disability is no factor."

"Yes, due to lack of trained staff."

"Yes - client must be at least 4 months delayed in the developmental skill areas."

"None too severely delayed."

"Yes, if interfered with ability to give needed services."

QUESTION 16: "Are there age limits for admission or discharge?"

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "No"          | 14            | 26.4%          |
| "Yes"         | 18            | 34.0%          |
| "N.A."        | 1             | 1.9%           |
| No answer     | 20            | 37.7%          |

Comments mostly specified the exact age limits.



Comments were as follows:

"Theoretically 6-13, but when census low, extend both ends."

"Yes, over 25."

"Eighteen for admission, none for discharge."

"Yes, 16 and up."

"No--infant stimulation program."

"For out-patients no, for program treatment yes."

"Yes, birth to 18."

"Yes, birth to 21."

"Yes, 16 generally minimum, no maximum."

"Yes, 18 years or older."

"Yes, 3-23."

"Yes, 0-5."

QUESTION 17: "How are services for clients paid for?"

| <u>Answer</u>              | <u>Number</u> | <u>Percent</u> |
|----------------------------|---------------|----------------|
| "Public" (exclusively)     | 8             | 15.1%          |
| "Private" (exclusively)    | 0             | 0%             |
| "Both, public and private" | 23            | 43.4%          |
| "N.A."                     | 1             | 1.9%           |
| No answer                  | 21            | 39.6%          |

Many responses indicated that public funds are available but families are often asked to pay on a sliding scale in addition to public funding from state and federal and third party payor sources. Title XX money is used in 6 Community Mental Health Centers.

Comments were as follows:

"By state and federal funds. When found eligible for WV services, there may be an economic means test for some services."

"Contracts with State Health Department."

"State funds, Title XX and adjusted payment by family."

"Public agencies - education agencies and families."

"State-operated ICF funding."

"Welfare, charity, insurance."

"Public, but if patient can afford it, \$5.00 a day."

"State funds and sliding scale for family."

"Third party payor, medicaid, etc. and sliding scale depending on income."

"County Board of Education; WV Department of Health."

"State reimbursement - 3rd party payor contract (Department of Welfare) and depending on ability to pay fees."

"Title XX, state, county; out-of-state clients pay fees on sliding scale."

"CMH program; private pay based on income."

"State and local support. Private non-profit organization - payment depends on referral and type of service."

"Third party payors or client if able to pay."

"By charging fees (\$25.00 mo. blanket fee regardless how much therapy is received). If parents are unable to pay, we try to find a person or organization which will sponsor child's therapy. If necessary, we will sponsor the therapy. We are funded by United Way."

"Taxes, state money, Medicaid."

"SSI check and MHC funds."

"Dept. of Voc. Reh. contracts with state health department."

"Title I, Title IX, state and federal, third party, and parents."

QUESTION 18: "Is your agency/institution interested in serving autistic citizens as a matter of policy (even if you do not now serve them)?"

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "No"          | 12            | 22.6%          |
| "Yes"         | 27            | 50.9%          |
| No answer     | 12            | 22.6%          |
| Comment only  | 2             | 3.7%           |

From the many positive responses, it is evident that some facilities are very willing to serve autistic clients, but acknowledge many limitations, particularly in the area of trained, experienced staff, and funding.

Comments were as follows:

Positive

"Physicians on staff have attended autism conferences."

"Until recently we have not been viewed as an appropriate placement for autistic persons; with a recent state agency decision to develop a program here for autistic persons, this stands to change."

"Nurses are encouraged to go to autism conferences."

"Our doctors gave physicals to autistic children in summer camp at Marshall University."

"We do not feel we have the population for this service."

"We want to provide services to community, education, and patients."

"If the need is there now - no need a few years ago."

"We would go by decree of WV Department of Education - by state standards."

"Absolutely interested."

"If feasible and appropriate services could be provided."

"Primary interest in MR."

"Only for medical part."

"Public welfare agencies must serve all individuals in need within the limits of budgets and other resources."

"Yes, pending trained staff."

"Presently cannot offer full range of services."

#### Negative

"No, we are not interested, because we have only outpatient care at our MHC with no placement programs for autistic."

"No - due to present limitations of staff and funds."

#### Comment only

"If the need is there - no need a few years ago."

"Questionable."

QUESTION 19: "If so, what additional resources or support would you need to serve them? (e.g., more trained staff, more space)"

Most responses suggested more trained staff, more information on autism and more appropriate physical facilities. Several indicate an interest in working with the school system in their community in regard to programming. The need for better case identification is also expressed.

Comments were as follows:

"More trained staff." (5 identical responses)

"More personnel, more and appropriate physical facilities."

"None." (hospital)

"More staff trained in education."  
 "More, better trained staff."  
 "More training, more information on autism."  
 "More trained staff; autistic clients."  
 "Nice housing facilities for diagnostic work-up."  
 "Coordination with well-trained teachers in school system."  
 "Additional training; education for current staff; additional staff for community education; community resource development."  
 "Staff and space; interest in providing programming with public schools."  
 "Staff, programming."  
 "More training for staff, more of a need."  
 "Staff and space, additional funds for transportation for scattered population."  
 "Would not materialize."  
 "Additional training and case finding."  
 "Different purpose of program."  
 "Improved skills for higher functioning; only for evaluation at present."  
 "Possibly more trained personnel."  
 "Training in autism."  
 "More trained staff; improving of the facility."  
 "Space, training."  
 "More training in working specifically with autistic persons."

QUESTION 20: "Do you consider your institution/agency an appropriate placement for an autistic person?"

| <u>Answer</u> | <u>Number</u> | <u>Percent</u> |
|---------------|---------------|----------------|
| "No"          | 23            | 43.4%          |
| "Yes"         | 12            | 22.6%          |
| "N.A."        | 1             | 1.9%           |
| No answer     | 17            | 32.1%          |

Responses indicate that most do not feel they can provide an appropriate placement at the present time.

Comments were as follows:

NO

"No need in the past."

"No until recently. State agency level decision has been made to



develop program here - 'no' stands to change."

"Not currently."

"Not at present."

"No; recommend structured school classroom."

"Not at present."

"No; new community priority: children's services."

"Not yet, as program expands."

"No, only if clients have additional medical problem to the autism."

"No, more participation in sheltered workshops and work adjustment programs possible."

"Currently no special placement available. A few placements are possible with Medley special funding."

"Not in its present form. Programs for DD children can take 1-2 autistic children but no adequate treatment program."

YES

"Yes, but mostly for diagnostic work up."

"Yes, with appropriate training."

"Yes, if severely delayed and cannot function in school setting."

"Yes, in some instances; e.g., if comprehensive services of WV Reh. Center were indicated."

"Yes, if #19 becomes a reality; (more trained staff, improvement of facility)."



PREFACE TO SURVEY TABLE

The blank space in the Table means administrators or other persons filling out the questionnaire did not respond to that question. In case of a telephone interview, we did not ask each single question.

In 1981, when we started the survey, we initially used the Annual Report 1977-1978, of the West Virginia Department of Health as our source for state hospitals and centers. We updated the list when the Departmental Directory, 1982, was published by the West Virginia Department of Health.

Survey Questions 1. through 3.  
Community Mental Health Centers, Hospitals/ Clinics

| NAMES                                                 | 1. Autistic or autistic-like currently served |     |                                 | 2. Served before |     | 3. Identified                          |
|-------------------------------------------------------|-----------------------------------------------|-----|---------------------------------|------------------|-----|----------------------------------------|
|                                                       | No                                            | Yes | Comments                        | No               | Yes | Number                                 |
| COMMUNITY MENTAL HEALTH CENTERS                       |                                               |     |                                 |                  |     |                                        |
| Appalachian MHC, Elkins                               |                                               | X   |                                 | X                |     | 1                                      |
| Central Dist. MHC, Clarksburg                         |                                               | X   |                                 |                  |     | 2                                      |
| Developmental Center, Keyser                          | X                                             |     |                                 | Unknown          |     | 0                                      |
| Eastern Panhandle MHC, Martinsburg                    | X                                             |     |                                 |                  | X   | 2                                      |
| Eastern Panhandle Training Center, Martinsburg        |                                               | X   | 1 out of case load of 110       | N.A.             |     | 1                                      |
| FMRS MH Council, Adult Training Center, Scarbro       | X                                             |     |                                 |                  |     |                                        |
| *Green Acres Regional Center, Lesage                  |                                               | X   | retarded childr. w/ A-like beh. |                  | X   | a few with autistic-like beh           |
| Hampshire County Special Services, Romney             |                                               | X   |                                 |                  |     | 2 A-like with multiple handicaps       |
| Hancock Brooke MHC, Weirton                           |                                               | X   | very few                        |                  |     | 6 during past 6 years                  |
| Logan-Mingo Area MH, Inc.                             |                                               | X   |                                 |                  | X   | 2                                      |
| Northern Panhandle MHC, Wheeling                      |                                               | X   |                                 | N.A.             |     | 5                                      |
| Potomac Compr. Diagn. & Guid. Center, Romney          |                                               | X   |                                 |                  |     | No collected data; many w/ confl. diag |
| Potomac Highlands Adult Train. Center, Petersburg     |                                               | X   | 1 who has not been diagnosed    |                  |     | 1                                      |
| Potomac Highlands MH Guild, Franklin                  | X                                             |     |                                 |                  | X   | 1                                      |
| Potomac Highlands, MH. Guild, Petersburg              |                                               | X   |                                 | N.A.             |     | 3                                      |
| *Prestera Center for MH, Huntington                   | X                                             |     | No active cases                 |                  |     |                                        |
| Seneca MH/MR Council, Summersville                    | X                                             |     |                                 | X                |     | None                                   |
| *Shawnee Hills CMH/MR Center                          |                                               | X   | Some A-like                     |                  |     | A couple of pre-schoolers w/out diag   |
| Southern Highlands CMHC, Princeton                    | X                                             |     |                                 |                  | X   | 2                                      |
| Southern Highlands CMHC--Guyandotte & Elkhorn, Satell |                                               | X   | children 0-5 w/ A-like beh.     |                  | X   | 8 since 1977                           |
| Western District Guidance Clinic, Parkersburg         |                                               | X   | Minimal                         | X                |     | 3                                      |
| HOSPITALS/CLINICS                                     |                                               |     |                                 |                  |     |                                        |
| *Cabell Huntington Hospital                           | X                                             |     |                                 |                  |     |                                        |
| Colin Anderson Center, St. Marys                      |                                               | X   |                                 | N.A.             |     | 5                                      |
| Concord, Yellow Spring                                |                                               | X   |                                 | N.A.             |     | 16-20                                  |
| Denmar, Hillsboro                                     | X                                             |     |                                 |                  |     |                                        |
| Fairmont Emergency Hospital                           | X                                             |     |                                 | X                |     | None                                   |
| *Highland Hosp. Children's Pav. Charleston            |                                               | X   | Would rather not                |                  | X   | 2                                      |

\*Information obtained by telephone interview

## Survey Question 1. through 3.

## Hospitals/Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                  | 1. Autistic or autistic-like currently served |     |                                         | 2. Served before |     | 3. Identified Number              |
|--------------------------------------------------------|-----------------------------------------------|-----|-----------------------------------------|------------------|-----|-----------------------------------|
|                                                        | No                                            | Yes | Comments                                | No               | Yes |                                   |
| Hopemont Hospital, Preston                             | X                                             |     |                                         | X                |     | N.A.                              |
| *Huntington Hospital, Psychia.D.                       | X                                             |     |                                         |                  |     |                                   |
| *Huntington State Hospital                             |                                               | X   | A few cases w/ A-like behavior          |                  |     | 18-23 with A-like characteristics |
| *Greenbrier Community Center, Lewisburg                |                                               | X   | Some A-like                             |                  | X   |                                   |
| Lakin State Hospital, Lakin                            | X                                             |     | Not generally                           |                  | X   | 2                                 |
| *Marshall Univ. Fam. Practice<br>Huntington            | X                                             |     |                                         |                  |     |                                   |
| Pinecrest Hospital, Beckley                            | X                                             |     |                                         | X                |     | 0                                 |
| Spencer Hospital, Spencer                              | X                                             |     | None diagnosed as such                  |                  |     | 0                                 |
| *St. Mary's Hospital, Huntington                       | X                                             |     | Only for acute patients                 | X                |     | 0                                 |
| Welch Emergency Hospital, Welch                        | X                                             |     |                                         |                  | X   |                                   |
| Weston State Hospital, Weston                          | X                                             |     | Currently only serve adults             |                  |     |                                   |
| *WVU Med. Ctr., Charleston, Ped. Dept.                 | X                                             |     | See some A-like in Behavior Clinic      |                  |     |                                   |
| *WVU Med. Ctr. Charleston, Psychia. Dept.              |                                               | X   | To confirm diagnosis                    |                  |     |                                   |
| *WVU Med. Ctr., Morgantown, Ped. Dept.                 | X                                             |     | Refer all autistic clients to Psychia.  |                  |     |                                   |
| *WVU Med. Ctr., Morgantown, Psychia. Dept.             |                                               | X   | Diagnostic work up                      |                  | X   | 4-5                               |
| AGENCIES                                               |                                               |     |                                         |                  |     |                                   |
| *Center for Independent Living, Huntington             | X                                             |     | Presently only serve phys. disabled     | X                |     |                                   |
| Cerebral Palsy Council, Cabell County, Huntington      |                                               | X   | 5 with autistic tendencies              | X                |     | 0                                 |
| *Children and Family Service Association, Wheeling     | X                                             |     |                                         |                  |     |                                   |
| *Crippled Children, Dept. of Welf. Huntington          |                                               | X   | For audiological care - brainstem test  |                  | X   | 0                                 |
| *Good Will Industries, Huntington                      | X                                             |     | Only for evaluation services            |                  | X   | 2                                 |
| Vocational Rehabilitation, Institute                   |                                               | X   | WV Reh. Ctr. Branch Offices & Distr. O. |                  | X   |                                   |
| *WVABC, Parkersburg                                    | X                                             |     | Most with MR or CP                      |                  |     |                                   |
| WV Dept. of Welf., Div. of Social Services, Charleston |                                               | X   |                                         |                  |     | No statistics available           |
| HOMES                                                  |                                               |     |                                         |                  |     |                                   |
| Andrew S. Rowan Memorial Home, Sweet Springs           | X                                             |     |                                         | X                |     |                                   |
| Elkins Group Home, Elkins                              |                                               | X   |                                         |                  | X   | 1                                 |
| SCHOOLS                                                |                                               |     |                                         |                  |     |                                   |
| WV School for the Deaf & Blind, Romney                 | X                                             |     |                                         | X                |     |                                   |



Survey Questions 4. through 6.  
Community Mental Health Centers, Hospitals/Clinics

| NAMES                                                     | 4. Formal diagnosis |                                  | 5. Incoming referrals                           | 6. Outgoing referrals                             |
|-----------------------------------------------------------|---------------------|----------------------------------|-------------------------------------------------|---------------------------------------------------|
|                                                           | No.                 | By whom?                         | By whom?                                        | To whom?                                          |
| <b>COMMUNITY MENTAL HEALTH CENTERS</b>                    |                     |                                  |                                                 |                                                   |
| Appalachian MHC, Elkins                                   | 1                   | Judevine Center<br>St. Louis, MO | Public School                                   | WVSAC                                             |
| Central Dist. MHC, Clarksburg                             | 0                   |                                  | local MDs, agencies,<br>clinics, parents        | WVSAC, State hotline                              |
| Developmental Center, Keyser                              | 0                   |                                  | N.A.                                            | N.A.                                              |
| Eastern Panhandle MHC,<br>Martinsburg                     | 1                   | psychiatrist<br>in Charleston    | usual systems - MDs,<br>schools, families       | Colin Anderson (Home-<br>Life Program)            |
| Eastern Panhandle Training<br>Center, Martinsburg         | 1                   |                                  | any source - agencies<br>families               | Done on individual bas.                           |
| PHRS MH Council, Adult<br>Training Center, Scarbro        |                     |                                  |                                                 |                                                   |
| *Green Acres Regional Center,<br>Lessa                    | 0                   | MA w/ A-like<br>features - MDs   |                                                 | Ruth Sullivan                                     |
| Hampshire County Special<br>Services, Romney              | 0                   | None have been<br>labeled        | Instit. referrals or<br>Dep. of Health          | Dep. of Health                                    |
| Hancock Brooke MHC, Weirton                               | 3                   |                                  | Families, schools                               | Autism Services Ctr.<br>Huntington                |
| Logan-Mingo Area MH, Inc.                                 | 1                   |                                  | various community agency<br>MDs, families       | So far we have serviced<br>any child in need      |
| Northern Panhandle MHC,<br>Wheeling                       | 5                   | MDs, WVU MC<br>MD at W/2 MHC     | Other agencies, Wheel-<br>ing Soc. for Crippled | Schools w/ self-cont.<br>classes, out-of-state    |
| Potomac Compr. Diagn. & Guid.<br>Center, Romney           | N.A.                |                                  | Any source in the Ctr's<br>12 county area       | Usually not referred if<br>community has services |
| Potomac Highlands Adult Train.<br>Center, Petersburg      | 0                   |                                  | Schools and families                            | Potomac Compr. Diagn.<br>& Guid. Ctr. Inc., Roma  |
| Potomac Highlands MH Guild,<br>Franklin                   | 1                   | Charles Shed<br>Academy, KY      | N.A.                                            | N.A.                                              |
| Potomac Highlands, MH. Guild,<br>Petersburg               | 3                   | Dr. Skye Payne<br>Ph.D.          | School                                          | Schools, PCDC, WV School<br>for the Deaf & Blind  |
| *Prestera Center for MH,<br>Huntington                    |                     |                                  |                                                 |                                                   |
| Seneca MH/MR Council,<br>Summersville                     | 0                   |                                  | N.A.                                            | Greenbrier Center if<br>young, Weston if adult    |
| *Shavnee Hills CMH/MR Center                              | 0                   |                                  | MDs, Department of<br>Welfare                   | Kanawha Board of Ed.<br>Beh. Disord. in Edison    |
| Southern Highlands CMHC,<br>Princeton                     | 2                   | Diagnostic Ctr.                  | MDs, teachers,<br>private                       | Diagnostic Ctr.,<br>school system                 |
| Southern Highlands CMHC--<br>Guyandotte & Elkhorn, Satell | 2                   | WVU in Charles-<br>ton           | MDs, Dept. of Welf. &<br>Health, parents        | 2 referrals to Colin<br>Anderson's Hope Prog.     |
| Western District Guidance<br>Clinic, Parkersburg          | 3                   | Psychologists<br>Psychiatrists   | Families, school<br>system                      | 1 referral to State<br>Dept. of Institutions      |
| <b>HOSPITALS/CLINICS</b>                                  |                     |                                  |                                                 |                                                   |
| *Cabell Huntington Hospital                               | 0                   | No clients who<br>needed diagn.  |                                                 |                                                   |
| Colin Anderson Center,<br>St. Marys                       |                     | Diag. by psy-<br>chi., A spec.   | CMHCs, inquiries by<br>county schools           | CMHCs, Dept. of Health<br>Dept. of Ed. schools    |
| Concord, Yellow Spring                                    | 16-<br>20           | Psychologists<br>MDs, educators  | agencies, MDs,<br>families                      | Variety of programs, dep-<br>on need              |
| Denmar, Hillsboro                                         |                     |                                  |                                                 |                                                   |
| Fairmont Emergency Hospital                               | 0                   |                                  | N.A.                                            | Valley MHC                                        |
| *Highland Hosp. Children's Pav.<br>Charleston             | 2                   | 1 staff, 1<br>private            | parents, teachers, MDs                          | ASC, Webster MHC                                  |



## Survey Questions 4. through 6.

## Hospitals/Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                  | 4. Formal diagnosis                  |                                | 5. Incoming referral                        | 6. Outgoing referral                                |
|--------------------------------------------------------|--------------------------------------|--------------------------------|---------------------------------------------|-----------------------------------------------------|
|                                                        | No.                                  | By whom?                       | By whom?                                    | To whom?                                            |
| Hopemont Hospital, Preston                             | N.A.                                 |                                | Not referred                                | Admissions process done by Dept. of Health          |
| *Huntington Hospital, Psychia.D.                       |                                      |                                |                                             |                                                     |
| *Huntington State Hospital                             |                                      |                                |                                             | If mainly retarded, part in educ. & recreat. progr. |
| *Greenbrier Community Center, Lewisburg                |                                      |                                |                                             |                                                     |
| Lakin State Hospital, Lakin                            | 0                                    |                                | Subjectively - 3 during past 2 years        | Mrs. Sullivan, Marshall University                  |
| *Marshall Univ. Fam. Practice Huntington               |                                      |                                |                                             |                                                     |
| Pinecrest Hospital, Beckley                            | 0                                    |                                | None                                        | No referrals                                        |
| Spencer Hospital, Spencer                              | 0                                    |                                | CMHC or courts                              | MHC or court                                        |
| *St. Mary's Hospital, Huntington                       | 0                                    |                                | Only see autistic w/ other probl., seiz.    |                                                     |
| Welch Emergency Hospital, Welch                        |                                      |                                |                                             | Elkhorn MHC                                         |
| Weston State Hospital, Weston                          |                                      |                                |                                             |                                                     |
| *WVU Med. Ctr., Charleston, Ped. Dept.                 | 0 in sem. Clinic 1 yr. twice monthly |                                | Not referred                                | Shawnee Hills, Ruth Sullivan                        |
| *WVU Med. Ctr. Charleston, Psychia. Dept.              |                                      |                                | Clients referred from all over state        | CMHC, back to schools                               |
| *WVU Med. Ctr., Morgantown, Ped. Dept.                 |                                      |                                |                                             | Dr. Kelley in Psychia. Dept. at WVU Morgantown      |
| *WVU Med. Ctr., Morgantown, Psychia. Dept.             |                                      | Diagnosed them all along       | Through regular clin. 4 years ago had A Ch. | School system                                       |
| AGENCIES                                               |                                      |                                |                                             |                                                     |
| *Center for Independent Living, Huntington             |                                      |                                |                                             |                                                     |
| Cerebral Palsy Council, Cabell County, Huntington      | Not known                            |                                | N.A.                                        | Green Acres, Prestera MHC, sch. ch. dev. ap.        |
| *Children and Family Service Association, Wheeling     |                                      |                                |                                             | Northern Panhandle MHC                              |
| *Crippled Children, Dept. of Welf 2 Huntington         |                                      | Huntington psychologists       | Soc. Sec. Administr.                        | Ruth Sullivan, school system                        |
| *Good Will Industries, Huntington                      |                                      |                                | Autism Services Ctr.                        | Board of Education                                  |
| Vocational Rehabilitation, Institute                   | Not known                            | Aut. clients encoded MR. disor | MRs, psychologists, self-referral, ed. dt.  | CMHC, DVR, and education agencies                   |
| *WVARC, Parkersburg                                    | Not known                            |                                |                                             | CMHC, school programs                               |
| WV Dept. of Welf., Div. of Social Services, Charleston | Not known                            |                                | Parents, other agency                       | CMHC, Boards of Educ. other agencies                |
| HOMES                                                  |                                      |                                |                                             |                                                     |
| Andrew S. Rowan Memorial Home, Sweet Springs           | 0                                    |                                |                                             |                                                     |
| Elkins Group Home, Elkins                              | 0                                    |                                | Dev. Dis. worker or state institutions      | Potomac Diagn. Center, Romney                       |
| SCHOOLS                                                |                                      |                                |                                             |                                                     |
| WV School for the Deaf & Blind, Romney                 |                                      |                                | N.A.                                        | N.A.                                                |

## Survey Questions 7. through 9.

## Community Mental Health Centers, Hospitals/ Clinics

| NAMES                                                 | 7. Specific program |     |                             | 8. Autistic come to facility--how often? |     |                               | 9. Qualifications of teachers/staff              |
|-------------------------------------------------------|---------------------|-----|-----------------------------|------------------------------------------|-----|-------------------------------|--------------------------------------------------|
|                                                       | No                  | Yes | Comments                    | No                                       | Yes | Comments                      |                                                  |
| COMMUNITY MENTAL HEALTH CENTERS                       |                     |     |                             |                                          |     |                               |                                                  |
| Appalachian MHC, Elkins                               | X                   |     |                             | X                                        |     |                               | No specific qualific., workshops & programs      |
| Central Dist. MHC, Clarksburg                         | X                   |     |                             |                                          | X   | Daily                         | Certified speech/lang. therapists, psycho., etc. |
| Developmental Center, Keyser                          | X                   |     |                             | X                                        |     |                               | Minimal                                          |
| Eastern Panhandle MHC, Martinsburg                    | X                   |     |                             | X                                        |     | None now                      | Degrees & training as psychol. soc. work. etc.   |
| Eastern Panhandle Training Center, Martinsburg        | X                   |     | Sheltered work shops        |                                          | X   | Daily                         | None                                             |
| PHRS MH Council, Adult Training Center, Scarbro       | X                   |     |                             |                                          |     |                               |                                                  |
| *Green Acres Regional Center, Lesage                  | X                   |     |                             | X                                        |     | No programs                   |                                                  |
| Hampshire County Special Services, Romney             | X                   |     |                             |                                          | X   | A-like people come daily      | SD & MR certification                            |
| Hancock Brooke MHC, Weirton                           | X                   |     |                             |                                          | X   | Usually for diagnostics       | No formal program available                      |
| Logan-Mingo Area MH, Inc.                             | X                   |     | Infant stim. pre-school p.  | X                                        |     |                               | None                                             |
| Northern Panhandle MHC, Wheeling                      | X                   |     | Ancillary services          |                                          | X   | Weekly for beh. managem.      | Exp. in agency's spec. curric. for autistic      |
| Potomac Compr. Diagn. & Guid. Center, Romney          | X                   |     |                             |                                          | X   | Monthly visits                | Resid. setting exp., 1 worked w/ A in CMHC       |
| Potomac Highlands Adult Train. Center, Petersburg     | X                   |     |                             |                                          | X   | 1 client comes daily          | Lim. qualif., staff worked w/ MR adults          |
| Potomac Highlands MH Guild, Franklin                  | X                   |     |                             | X                                        |     |                               | Minim. in-service train. & workshops             |
| Potomac Highlands, MH. Guild, Petersburg              | X                   |     |                             |                                          | X   | Training daily tests annually | None                                             |
| *Prestera Center for MH, Huntington                   | X                   |     | New children's program      |                                          |     |                               |                                                  |
| Seneca MH/MR Council, Summersville                    | X                   |     |                             | X                                        |     |                               | Psychologists & psychiatrists                    |
| *Shawnee Hills CMH/MR Center                          | X                   |     | 1 attends MR prog., 1 act.  |                                          |     | Twice a week prog. particip.  | None spec., special ed. in undergrad. degr.      |
| Southern Highlands CMHC, Princeton                    | X                   |     |                             | X                                        |     |                               | Psychologists & soc. workers; some exposure      |
| Southern Highlands CMHC--Guyandotte & Elkhorn, Satell | X                   |     | DCP counsel. prog. for fam. | X                                        |     | Home-based serv. weekly       | M.A. in Spec. Ed., B.A. in psychology            |
| Western District Guidance Clinic, Parkersburg         | X                   |     | 1 attends MR prog., 1 act.  |                                          | X   | Twice a week                  | B.A. degrees in help. professions area           |
| HOSPITALS/CLINICS                                     |                     |     |                             |                                          |     |                               |                                                  |
| *Cabell Huntington Hospital                           | X                   |     |                             |                                          |     |                               |                                                  |
| Colin Anderson Center, St. Marys                      | X                   |     | As yet no spec. prog.       |                                          | X   | In residence                  | Prof. staff college tr. in spec. ed.             |
| Concord, Yellow Spring                                | X                   |     | No sep. pro.                |                                          |     | Residential                   | Univ. training, in-service tr. & experience      |
| Denmar, Hillsboro                                     | X                   |     |                             |                                          |     |                               |                                                  |
| Fairmont Emergency Hospital                           | X                   |     |                             | X                                        |     |                               | None                                             |
| *Highland Hosp. Children's Pav. Charleston            | X                   |     |                             |                                          | X   | 2 have come                   | No formal tr. or exp. 1 psychol. tr. in A        |

Survey Questions 7. through 9.  
Hospitals/Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                  | 7. Specific program |     |                              | 8. Autistic come to facility--how often? |     |                                | 9. Qualifications of teachers/staff   |
|--------------------------------------------------------|---------------------|-----|------------------------------|------------------------------------------|-----|--------------------------------|---------------------------------------|
|                                                        | No                  | Yes | Comments                     | No                                       | Yes | Comments                       |                                       |
| Hopemont Hospital, Preston                             | X                   |     |                              |                                          |     | N.A.                           | None                                  |
| *Huntington Hospital, Psychia.D.                       | X                   |     |                              |                                          |     |                                |                                       |
| *Huntington State Hospital                             | X                   |     |                              |                                          |     | Residential                    | Educationist background               |
| *Greenbrier Community Center, Lewisburg                | X                   |     |                              |                                          |     |                                |                                       |
| Lakin State Hospital, Lakin                            | X                   |     |                              | X                                        |     |                                | Staff is certified e.g., therapists   |
| *Marshall Univ. Fam. Practice Huntington               | X                   |     |                              | X                                        |     |                                |                                       |
| Pinecrest Hospital, Beckley                            | X                   |     |                              | X                                        |     |                                | None                                  |
| Spencer Hospital, Spencer                              | X                   |     |                              |                                          | X   | With referral from CMHC, court | None                                  |
| *St. Mary's Hospital, Huntington                       | X                   |     |                              |                                          |     |                                |                                       |
| Welch Emergency Hospital, Welch                        | X                   |     |                              |                                          | X   |                                | Nursing background                    |
| Weston State Hospital, Weston                          | X                   |     |                              |                                          |     |                                |                                       |
| *WVU Med. Ctr., Charleston, Ped. Dept.                 | X                   |     |                              |                                          |     |                                | MDs, medical staff                    |
| *WVU Med. Ctr. Charleston, Psychia. Dept.              | X                   |     | No treatment                 |                                          |     |                                |                                       |
| *WVU Med. Ctr., Morgantown, Ped. Dept.                 | X                   |     |                              |                                          |     | Behavior Clinic twice a month  |                                       |
| *WVU Med. Ctr., Morgantown, Psychia. Dept.             | X                   |     | Only diagnostic format       |                                          |     |                                | MDs, psychologist not Judevine tr.    |
| AGENCIES                                               |                     |     |                              |                                          |     |                                |                                       |
| *Center for Independent Living, Huntington             | X                   |     |                              |                                          |     |                                |                                       |
| Cerebral Palsy Council, Cabell County, Huntington      | X                   |     |                              | X                                        |     |                                | None                                  |
| *Children and Family Service Association, Wheeling     | X                   |     |                              |                                          | X   | Outpatient only for counseling |                                       |
| *Crippled Children, Dept. of Welf. Huntington          | X                   |     |                              |                                          | X   | 1 child                        | No particular qualifications          |
| *Good Will Industries, Huntington                      | X                   |     | work-adjustm. pr. & dial rid |                                          |     |                                | None                                  |
| Vocational Rehabilitation, Institute                   | X                   |     |                              |                                          | X   | Could be daily at WV Reh. Ctr. | Licensed and certified in their field |
| *WVARC, Parkersburg                                    | X                   |     |                              |                                          |     |                                | None                                  |
| WV Dept. of Welf., Div. of Social Services, Charleston | X                   |     |                              |                                          |     | Unknown                        | No spec. training                     |
| HOMES                                                  |                     |     |                              |                                          |     |                                |                                       |
| Andrew S. Rowan Memorial Home, Sweet Springs           | X                   |     |                              |                                          |     |                                |                                       |
| Elkins Group Home, Elkins                              | X                   |     | Group home program           |                                          | X   | 1 in 6 years                   | MR counselors, BA in psychology       |
| SCHOOLS                                                |                     |     |                              |                                          |     |                                |                                       |
| WV School for the Deaf & Blind, Romney                 | X                   |     |                              |                                          |     |                                | None                                  |



## Survey Questions 10. through 12.

## Community Mental Health Centers, Hospitals/ Clinics

| NAMES                                                     | 10. Formal training of teachers/staff |                                      | 11. Kind and extent of experience<br>Comments                                   | 12. Teachers/staff without formal tr. - related training?<br>Comments |
|-----------------------------------------------------------|---------------------------------------|--------------------------------------|---------------------------------------------------------------------------------|-----------------------------------------------------------------------|
|                                                           | Number                                | Location                             |                                                                                 |                                                                       |
| COMMUNITY MENTAL HEALTH CENTERS                           |                                       |                                      |                                                                                 |                                                                       |
| Appalachian MHC, Elkins                                   | None                                  |                                      | Limited, if any                                                                 | 14 staff in DO program<br>10 in Child. Prog.                          |
| Central Dist. MHC, Clarksburg                             | None                                  |                                      | 5% are behav. train-<br>ed                                                      | No formal but all<br>related training                                 |
| Developmental Center, Keyser                              | None                                  |                                      | None                                                                            | None with training or<br>experience                                   |
| Eastern Panhandle MHC,<br>Martinsburg                     | None                                  |                                      | None                                                                            | None with training or<br>experience                                   |
| Eastern Panhandle Training<br>Center, Martinsburg         | None                                  |                                      | Practical exp. w/<br>1 autistic client                                          | 21 no formal training,<br>but related training                        |
| FHRS MH Council, Adult<br>Training Center, Scarbro        |                                       |                                      |                                                                                 |                                                                       |
| Green Acres Regional Center,<br>Lessa                     |                                       |                                      |                                                                                 |                                                                       |
| Hampshire County Special<br>Services, Romney              | None                                  |                                      | On-the job                                                                      | 2 related training                                                    |
| Hancock Brooke MHC, Weirton                               | None                                  |                                      | N.A.                                                                            | N.A.                                                                  |
| Logan-Mingo Area MH, Inc.<br>Logan                        | No                                    |                                      | Various workshops &<br>in-service tr.                                           | No spec. staff design.<br>to work w/ autistic                         |
| Northern Panhandle MHC,<br>Wheeling                       | None                                  |                                      | On-the job exper. at<br>NPMHC under sup. of MD                                  | Licensed clin. psychol.<br>cert. speech pathol.                       |
| Potomac Compr. Diagn. & Guid.<br>Center, Romney           | No                                    |                                      | Out-of-state exper.<br>in MHC & res. set.                                       | All have received in-<br>service training                             |
| Potomac Highlands Adult Train.<br>Center, Petersburg      | Staff m.<br>B.A. in H&E               | Graduate hrs<br>in MR                | All staff m. worked<br>w/ or since begin-<br>g. of MR; 1<br>staff m. experience | All 3 have not had<br>formal tr.<br>N.A.                              |
| Potomac Highlands MH Guild,<br>Franklin                   | None                                  |                                      | On-jobs, lim. exp.<br>at prev. jobs                                             | 29 have not had formal<br>tr. in A; some rel tr.                      |
| Potomac Highlands, MH. Guild,<br>Petersburg               | None                                  |                                      |                                                                                 |                                                                       |
| *Presters Center for MH,<br>Huntington                    |                                       |                                      |                                                                                 |                                                                       |
| Seneca MH/MR Council,<br>Summersville                     | None                                  | Gen. tr. in<br>sp. ed., gr.<br>prof. | None                                                                            | N.A.                                                                  |
| *Shawnee Hills CMH/MR Center                              | None                                  |                                      | None                                                                            | Some tr. w/ autistic<br>symp. sec. to severe DD                       |
| Southern Highlands CMHC,<br>Princeton                     | None                                  |                                      | No formal program                                                               | Psychology & soc.<br>work                                             |
| Southern Highlands CMHC--<br>Guyandotte & Elkhorn, Satell | None                                  |                                      | Informal tr. in home<br>for ED children in IA                                   | Spec. Ed. degrees w/<br>some exposure to A.                           |
| Western District Guidance<br>Clinic, Parkersburg          | None                                  |                                      | Very limited                                                                    | None have had formal<br>training                                      |
| HOSPITALS/CLINICS                                         |                                       |                                      |                                                                                 |                                                                       |
| *Cabell Huntington Hospital                               |                                       |                                      |                                                                                 |                                                                       |
| Colin Anderson Center,<br>St. Marys                       | None excl<br>w/ A                     |                                      | Supervised training<br>early child- adult                                       | Prof. pers. college de<br>certif. staff                               |
| Concord, Yellow Spring                                    | None                                  |                                      | Varies widely                                                                   | Residential training                                                  |
| Denmar, Hillsboro                                         |                                       |                                      |                                                                                 |                                                                       |
| Fairmont Emergency Hospital                               | None                                  |                                      | N.A.                                                                            | None                                                                  |
| *Highland Hosp. Children's Pav.<br>Charleston             |                                       |                                      |                                                                                 |                                                                       |



## Survey Questions 10. through 12.

## Hospitals/ Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                  | 10. Formal training of teachers/staff |                        | 11. Kind and extent of experience                | 12. Teachers/staff without formal tr. related training? |
|--------------------------------------------------------|---------------------------------------|------------------------|--------------------------------------------------|---------------------------------------------------------|
|                                                        | Number                                | Location               | Comments                                         |                                                         |
| Hopewell Hospital, Preston                             | None                                  |                        | None                                             | None                                                    |
| *Huntington Hospital, Psychia.D.                       |                                       |                        |                                                  |                                                         |
| *Huntington State Hospital                             |                                       |                        | Educational & recr.                              |                                                         |
| *Greenbrier Community Center, Lewisburg                |                                       |                        |                                                  |                                                         |
| Lakin State Hospital, Lakin                            | 2 unknown precisely                   |                        | N.A.                                             | N.A.                                                    |
| *Marshall Univ. Fam. Practice<br>Huntington            |                                       |                        |                                                  |                                                         |
| Pinecrest Hospital, Beckley                            | None                                  |                        | None                                             | None                                                    |
| Spencer Hospital, Spencer                              | None                                  |                        | None                                             | No staff w/ such trainine                               |
| *St. Mary's Hospital, Huntington                       |                                       |                        |                                                  |                                                         |
| Welch Emergency Hospital, Welch                        | 1                                     | Hope progr.            | 1 nursing staff has autistic child               | N.A.                                                    |
| Weston State Hospital, Weston                          |                                       |                        | Training ages 4-9                                |                                                         |
| *WVU Med. Ctr., Charleston, Ped. Dept.                 |                                       | Shawnee Hills          | 1 year<br>Ped. res. at Shawnee Hills & in clinic | Clinical training                                       |
| *WVU Med. Ctr. Charleston, Psychia. Dept.              | None                                  |                        | None                                             |                                                         |
| *WVU Med. Ctr., Morgantown, Ped. Dept.                 |                                       |                        |                                                  |                                                         |
| *WVU Med. Ctr., Morgantown, Psychia. Dept.             |                                       | Med. School            |                                                  |                                                         |
| AGENCIES                                               |                                       |                        |                                                  |                                                         |
| *Center for Independent Living, Huntington             |                                       |                        |                                                  | None                                                    |
| Cerebral Palsy Council, Cabell County, Huntington      | None                                  |                        | None                                             | None with formal training                               |
| *Children and Family Service Association, Wheeling     |                                       |                        |                                                  |                                                         |
| *Crippled Children, Dept. of Welf. Huntington          | None                                  |                        | Social worker only one contact w/ ch.            | Appropri. degree in their field & tr.                   |
| *Good Will Industries, Huntington                      | None                                  |                        | None                                             | None with formal training                               |
| Vocational Rehabilitation, Institute                   | None                                  | Attended semi by WVSAC | WV Reh. Ctr. limit exp. 1 no supervis.           | 10-12, some have sp. ed. tr., cert.                     |
| *WVARC, Parkersburg                                    | None                                  |                        | None                                             | None with formal tr.                                    |
| WV Dept. of Welf., Div. of Social Services, Charleston | None                                  |                        | Unknown                                          | Unknown                                                 |
| HOMES                                                  |                                       |                        |                                                  |                                                         |
| Andrew S. Rowan Memorial Home, Sweet Springs           |                                       |                        |                                                  |                                                         |
| Elkins Group Home, Elkins                              | None                                  |                        | All staff at least 2-6 yrs. in gr. home          | All have had relat. training                            |
| SCHOOLS                                                |                                       |                        |                                                  |                                                         |
| WV School for the Deaf & Blind, Romney                 | None                                  |                        |                                                  | N.A.                                                    |

Survey Questions 13. through 15.  
Community Mental Health Centers, Hospitals/ Clinics

| NAMES                                                 | 13. Experience on non-trained teachers/staff            | 14. Classification of autistic clients      | 15. Severity criterion for adm/dis |     |                           |
|-------------------------------------------------------|---------------------------------------------------------|---------------------------------------------|------------------------------------|-----|---------------------------|
|                                                       | Comments                                                | Comments                                    | No                                 | Yes | Comments                  |
| COMMUNITY MENTAL HEALTH CENTERS                       |                                                         |                                             |                                    |     |                           |
| Appalachian MHC, Elkins                               |                                                         | Varies, depending on clinician who does ass |                                    | X   | Out-patient basis         |
| Central Dist. MHC, Clarksburg                         | Educational training; related job experience            | Not classified                              |                                    | X   |                           |
| Developmental Center, Keyser                          | None                                                    | Data not available                          |                                    |     | N.A.                      |
| Eastern Panhandle MHC, Martinsburg                    |                                                         | Autistic                                    |                                    | X   |                           |
| Eastern Panhandle Training Center, Martinsburg        | Practical training                                      | ED                                          |                                    | X   |                           |
| FMRS MH Council, Adult Training Center, Scarbro       |                                                         | Only developm. disab.                       |                                    |     |                           |
| *Green Acres Regional Center, Ledges                  |                                                         |                                             |                                    |     |                           |
| Hampshire County Special Services, Romney             |                                                         | Multi-handicapped                           |                                    |     |                           |
| Hancock Brooke MHC, Weirton                           | N.A.                                                    | Generally within BD                         |                                    | X   |                           |
| Logan-Mingo Area MH, Inc. Logan                       | N.A.                                                    | Pervasive developm. disorder, infant. A     |                                    | X   | Delay in dev. skills area |
| Northern Panhandle MHC, Wheeling                      | On-the-job experience                                   | BD—two have emotion. disturbance            |                                    | X   | Due to lack of tr. staff  |
| Potomac Compr. Diagn. & Guid. Center, Romney          | All have received in-service training                   | Not classified except as devl disabled      |                                    | X   |                           |
| Potomac Highlands Adult Train. Center, Petersburg     |                                                         | M.P.                                        |                                    | X   | No for adm. Yes for dis.  |
| Potomac Highlands MH Guild, Franklin                  | N.A.                                                    | N.A.                                        |                                    | X   |                           |
| Potomac Highlands, MH. Guild, Petersburg              | On-the-job training, lim. exp. - pre-school & post scho | Autistic                                    |                                    | X   |                           |
| *Presters Center for MH, Huntington                   |                                                         |                                             |                                    |     |                           |
| Seneca MH/MR Council, Summersville                    | None with experience                                    | N.A.                                        |                                    | X   | If too severe             |
| *Shavnee Hills CMH/MR Center                          |                                                         | Primarily profoundly retarded               |                                    | X   | None too sev. delayed     |
| Southern Highlands CMHC, Princeton                    | N.A.                                                    | Diagnosed by DSM III                        |                                    | X   |                           |
| Southern Highlands CMHC--Guyandotte & Elkhorn, Satell |                                                         | Formal autism diagn. or autistic tendenc.   |                                    | X   | 0-5, signif delay         |
| Western District Guidance Clinic, Parkersburg         |                                                         | Autistic, ED                                |                                    | X   |                           |
| HOSPITALS/CLINICS                                     |                                                         |                                             |                                    |     |                           |
| *Cabell Huntington Hospital                           |                                                         |                                             |                                    |     |                           |
| Col. M. Anderson Center, St. Marys                    | Supervised experience - early childh. - adult           | Autistic or autistic-like                   |                                    | X   | converse for discharge    |
| Concord, Yellow Spring                                | Varies widely                                           | They are not!                               |                                    | X   |                           |
| Denmar, Hillsboro                                     |                                                         |                                             |                                    |     |                           |
| Fairmont Emergency Hospital                           |                                                         |                                             |                                    |     | N.A.                      |
| *Highland Hosp. Children's Pav. Charleston            |                                                         | Autistic, questionable autism               |                                    | X   | Now, not past             |

Survey Questions 13. through 15.  
Hospitals/ Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                  | 13. Experience of non-trained teachers/staff | 14. Classification of autistic clients        | 15. Severity criterion for adm/dis |                               |
|--------------------------------------------------------|----------------------------------------------|-----------------------------------------------|------------------------------------|-------------------------------|
|                                                        | Comments                                     | Comments                                      | No                                 | Yes                           |
| Hopemont Hospital, Preston                             | N.A.                                         | N.A.                                          | X                                  | For admission                 |
| *Huntington Hospital, Psychia.D.                       |                                              |                                               |                                    |                               |
| *Huntington State Hospital                             |                                              |                                               |                                    |                               |
| *Greenbrier Community Center, Lewisburg                |                                              |                                               |                                    |                               |
| Lakin State Hospital, Lakin                            | N.A.                                         | N.A.                                          |                                    |                               |
| *Marshall Univ. Fam. Practice Huntington               |                                              |                                               |                                    |                               |
| Pinecrest Hospital, Beckley                            |                                              | N.A.                                          |                                    |                               |
| Spencer Hospital, Spencer                              | None to my knowledge                         | N.A.                                          | X                                  |                               |
| *St. Mary's Hospital, Huntington                       |                                              |                                               |                                    |                               |
| Welch Emergency Hospital, Welch                        | N.A.                                         | Elkins MHC classifies them                    |                                    | N.A.                          |
| Weston State Hospital, Weston                          |                                              |                                               |                                    |                               |
| *WVU Med. Ctr., Charleston, Ped. Dept.                 |                                              | Autistic-like beh.                            | X                                  |                               |
| *WVU Med. Ctr. Charleston, Psychia. Dept.              |                                              | Autistic DSM III criteria                     | X                                  |                               |
| *WVU Med. Ctr., Morgantown, Ped. Dept.                 |                                              | Autistic                                      | X                                  |                               |
| *WVU Med. Ctr., Morgantown, Psychia. Dept.             |                                              | Autistic                                      | X                                  | Only diagn.                   |
| AGENCIES                                               |                                              |                                               |                                    |                               |
| *Center for Independent Living, Huntington             |                                              | Severely disabled                             | X                                  | Must benefit                  |
| Cerebral Palsy Council, Cabell County, Huntington      | Experience only thru contact with families   | Autistic tendencies in addition to phys. hand | X                                  | If needed some cannot be prov |
| *Children and Family Service Association, Wheeling     |                                              |                                               |                                    |                               |
| *Crippled Children, Dept. of Welf Huntington           |                                              | 1 child hearing -imp. w/ autistic symptoms    | X                                  |                               |
| *Good Will Industries, Huntington                      |                                              | Autistic                                      | X                                  | Must benefit                  |
| Vocational Rehabilitation, Institute                   | Limited exp. at Reh. Ctr., no supervision    | Mental, emotional, MA, psychoneurotic         | X                                  |                               |
| *WVARC, Parkersburg                                    |                                              | MR or CP diagnosis                            | X                                  | Severity no factor            |
| WV Dept. of Welf., Div. of Social Services, Charleston | Unknown                                      | No special classific                          | X                                  |                               |
| HOMES                                                  |                                              |                                               |                                    |                               |
| Andrew S. Rowan Memorial Home, Sweet Springs           |                                              |                                               |                                    |                               |
| Elkins Group Home, Elkins                              | All staff at least 2-6 yrs. in gr. home      | BD                                            | X                                  |                               |
| SCHOOLS                                                |                                              |                                               |                                    |                               |
| WV School for the Deaf & Blind, Romney                 | N.A.                                         |                                               |                                    |                               |



## Survey Questions 16. through 18.

## Community Mental Health Centers, Hospitals/Clinics

| NAMES                                                 | 16. Age limits for admission & discharge | 17. Funding for services |                                | 18. Interest in serving autistic citizens |     | Comments                                |
|-------------------------------------------------------|------------------------------------------|--------------------------|--------------------------------|-------------------------------------------|-----|-----------------------------------------|
|                                                       | Age limits                               | Public                   | Private                        | No                                        | Yes |                                         |
| COMMUNITY MENTAL HEALTH CENTERS                       |                                          |                          |                                |                                           |     |                                         |
| Appalachian MHC, Elkins                               | No                                       | 3rd party                | Sliding scale                  |                                           | X   |                                         |
| Central Dist. MHC, Clarksburg                         | 0-5                                      | State, Wa Title 19       | parent                         |                                           | X   | Presently cannot offer full range       |
| Developmental Center, Keyser                          | Yes                                      | County Bd of Educat      | Ability                        |                                           |     | We go by decrees of WV Dept. of Ed.     |
| Eastern Panhandle MHC, Martinsburg                    | No                                       | State                    | Contract                       | X                                         |     |                                         |
| Eastern Panhandle Training Center, Martinsburg        | Yes                                      | Dept. of Voc. Reh.       |                                |                                           | X   |                                         |
| FHRS MH Council, Adult Training Center, Scarbro       | Yes--23 and over                         |                          |                                |                                           |     |                                         |
| *Green Acres Regional Center, Lesage                  |                                          |                          |                                |                                           |     |                                         |
| Hampshire County Special Services, Romney             |                                          |                          |                                |                                           |     |                                         |
| Hancock Brooke MHC, Weirton                           | No                                       | CMH progr                | Based on income                |                                           | X   |                                         |
| Logan-Mingo Area MH, Inc.                             | No                                       | WV Dept. of Health       | Ability                        | X                                         |     |                                         |
| Northern Panhandle MHC, Wheeling                      | No                                       |                          |                                |                                           | X   | Pending trained staff                   |
| Potomac Compr. Diagn. & Guid. Center, Romney          | No                                       | State & Local            | Depends on ref.                |                                           | X   | Absolutely                              |
| Potomac Highlands Adult Train. Center, Petersburg     | Yes--16 years and up                     | Title XX                 |                                |                                           | X   |                                         |
| Potomac Highlands MH Guild, Franklin                  | No                                       | 3rd party                | Ability                        |                                           | X   |                                         |
| Potomac Highlands, MH. Guild, Petersburg              | No                                       | Public & Private         |                                |                                           | X   |                                         |
| *Presters Center for MH, Huntington                   |                                          |                          |                                |                                           |     |                                         |
| Seneca MH/MR Council, Summersville                    | No--part-time out-patient treatment      | State, 3rd party cont.   | Clients                        |                                           | X   | If feasible & appro services can be pro |
| *Shawnee Hills CMH/MR Center                          | No; have infant stimulation program      | Title XX                 | For pre-school                 |                                           | X   | Primary interest MR                     |
| Southern Highlands CMHC, Princeton                    | No                                       | Title XX State           | Private insurance              |                                           | X   |                                         |
| Southern Highlands CMHC--Guyandotte & Elkhorn, Satell | Yes--up to 6                             | Title XX State, county   | Sliding scale                  | X                                         |     | Due to limited funds & staff            |
| Western District Guidance Clinic, Parkersburg         | For out-patients No. for program treatm. | Yes                      | Sliding scale                  |                                           |     | Questionable                            |
| HOSPITALS/CLINICS                                     |                                          |                          |                                |                                           |     |                                         |
| *Cabell Huntington Hospital                           |                                          |                          |                                |                                           | X   | Physicians have attended A confer.      |
| Colin Anderson Center, St. Marys                      | No                                       | State, Title XX          | Adjusted payment               | X                                         |     | Until recently                          |
| Con ord, Yellow Spring                                | Yes                                      | Agencies                 | Families                       |                                           | X   |                                         |
| Denmar, Hillsboro                                     |                                          | State                    |                                |                                           | X   |                                         |
| Fairmont Emergency Hospital                           | No                                       |                          | Handled by soc. serv. director |                                           |     |                                         |
| *Highland Hosp. Children's Pav. Charleston            | Theoretically 6-13, extended both ends   | Welfare                  |                                | X                                         |     | Prefer not                              |



## Survey Questions 16. through 18.

## Hospitals/Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                  | 16. Age limits for admission & discharge<br>Age limits | 17. Funding for services |               | 18. Interest in serving autistic citizens |     |                                   |
|--------------------------------------------------------|--------------------------------------------------------|--------------------------|---------------|-------------------------------------------|-----|-----------------------------------|
|                                                        |                                                        | Public                   | Private       | No                                        | Yes | Comments                          |
| Hopemont Hospital, Preston                             | Over 25                                                | Yes                      | \$5 a day     | X                                         |     |                                   |
| *Huntington Hospital, Psychia.D.                       |                                                        |                          |               |                                           |     |                                   |
| *Huntington State Hospital                             |                                                        | Yes                      |               |                                           | X   | Nurses are encouraged to go to    |
| *Greenbrier Community Center, Lewisburg                |                                                        |                          |               |                                           |     |                                   |
| Lakin State Hospital, Lakin                            |                                                        |                          |               |                                           |     |                                   |
| *Marshall Univ. Fam. Practice Huntington               |                                                        |                          |               |                                           |     |                                   |
| Pinecrest Hospital, Beckley                            |                                                        |                          |               |                                           |     |                                   |
| Spencer Hospital, Spencer                              | 18 for admission, none for discharge                   | State                    | Sliding scale | X                                         |     |                                   |
| *St. Mary's Hospital, Huntington                       |                                                        |                          |               |                                           |     |                                   |
| Welch Emergency Hospital, Welch                        | N.A.                                                   | N.A.                     |               |                                           | X   |                                   |
| Weston State Hospital, Weston                          |                                                        |                          |               |                                           |     |                                   |
| *WVU Med. Ctr., Charleston, Ped. Dept.                 |                                                        |                          |               |                                           | X   |                                   |
| *WVU Med. Ctr. Charleston, Psychia. Dept.              | No                                                     | Welfare, schools         | Same as other |                                           | X   | Want to give services             |
| *WVU Med. Ctr., Morgantown, Ped. Dept.                 |                                                        |                          |               |                                           |     |                                   |
| *WVU Med. Ctr., Morgantown, Psychia. Dept.             | No                                                     | Yes                      | Yes           |                                           | X   | If need is there                  |
| AGENCIES                                               |                                                        |                          |               |                                           |     |                                   |
| *Center for Independent Living, Huntington             |                                                        | Yes                      |               |                                           | X   | Definitely when expanding servi   |
| Cerebral Palsy Council, Cabell County, Huntington      | Birth to 18                                            | United Way               | 3rd party     |                                           |     |                                   |
| *Children and Family Service Association, Wheeling     |                                                        |                          |               |                                           |     |                                   |
| *Crippled Children, Dept. of Welf. Huntington          | Birth to 21                                            | Taxes, state Medicaid    |               |                                           | X   | Only for any medical part         |
| *Good Will Industries, Huntington                      | No maximum<br>Yes—16 minimum                           | X                        |               |                                           | X   |                                   |
| Vocational Rehabilitation, Institute                   | Yes—generally 16 minimum; no maximum                   | State & Federal          |               |                                           | X   |                                   |
| *WVARC, Parkersburg                                    |                                                        |                          |               |                                           |     |                                   |
| WV Dept. of Welf., Div. of Social Services, Charleston | No                                                     | Federal & State taxes    | Sliding Scale |                                           | X   | Public welfare agencies serve all |
| HOMES                                                  |                                                        |                          |               |                                           |     |                                   |
| Andrew S. Rowan Memorial Home, Sweet Springs           |                                                        |                          |               |                                           |     |                                   |
| Elkins Group Home, Elkins                              | 18 years or older                                      | SSI, MHC                 |               |                                           | X   |                                   |
| SCHOOLS                                                |                                                        |                          |               |                                           |     |                                   |
| WV School for the Deaf & Blind, Romney                 | Yes—3 to 23                                            | State, fed.              |               |                                           | X   |                                   |

## Survey Questions 19. and 20.

## Community Mental Health Centers, Hospitals/Clinics

| NAMES                                                     | 19. Resources & support needed<br>to serve autistic clients        | 20. Facility an appropriate<br>placement for autistic persons |     |                                                  |
|-----------------------------------------------------------|--------------------------------------------------------------------|---------------------------------------------------------------|-----|--------------------------------------------------|
|                                                           | Comments                                                           | No                                                            | Yes | Comments                                         |
| COMMUNITY MENTAL HEALTH CENTERS                           |                                                                    |                                                               |     |                                                  |
| Appalachian MHC, Elkins                                   | Additional training, education<br>for current staff, addit. staff  |                                                               | X   |                                                  |
| Central Dist. MHC, Clarksburg                             | More trained staff                                                 | X                                                             |     | Not in its present<br>form, no adequ. tr. pr.    |
| Developmental Center, Keyser                              | Training of staff                                                  |                                                               | X   | With appropr. tr.                                |
| Eastern Panhandle MHC,<br>Martinsburg                     |                                                                    |                                                               |     |                                                  |
| Eastern Panhandle Training<br>Center, Martinsburg         | More trained staff                                                 | X                                                             |     |                                                  |
| FHR5 MH Council, Adult<br>Training Center, Scarbro        |                                                                    |                                                               |     |                                                  |
| *Green Acres Regional Center,<br>Lesage                   |                                                                    |                                                               |     |                                                  |
| Hampshire County Special<br>Services, Romney              |                                                                    |                                                               |     |                                                  |
| Hancock Brooke MHC, Weirton                               | Staff & space, interest in<br>providing pr. w/ public schools      | X                                                             |     |                                                  |
| Logan-Mingo Area MH, Inc.                                 | More training in working spec.<br>with autistic persons            |                                                               | X   |                                                  |
| Northern Panhandle MHC,<br>Wheeling                       | More trained staff                                                 |                                                               | X   | If #19 becomes reality                           |
| Potomac Compr. Diagn. & Guid.<br>Center, Romney           | More training                                                      |                                                               | X   |                                                  |
| Potomac Highlands Adult Train.<br>Center, Petersburg      | More training for staff                                            |                                                               | X   |                                                  |
| Potomac Highlands MH Guild,<br>Franklin                   | Staff, programming                                                 | X                                                             |     |                                                  |
| Potomac Highlands, MH. Guild,<br>Petersburg               | More of a need,<br>more training for staff                         |                                                               | X   |                                                  |
| *Prestra Center for MH,<br>Huntington                     |                                                                    | X                                                             |     | New community priority<br>children's services    |
| Seneca MH/MR Council,<br>Summersville                     | Staff, space, addit. funds for<br>transportation for scattered cl. |                                                               |     |                                                  |
| *Shawnee Hills CMH/MR Center                              | Would not materialize                                              |                                                               | X   | If severely delayed &<br>cannot funct. in school |
| Southern Highlands CMHC,<br>Princeton                     | Additional training & case find.                                   | X                                                             |     |                                                  |
| Southern Highlands CMHC--<br>Guyandotte & Elkhorn, Satell | See #18                                                            | X                                                             |     | Recommend structured<br>school classroom         |
| Western District Guidance<br>Clinic, Parkersburg          |                                                                    |                                                               |     |                                                  |
| HOSPITALS/CLINICS                                         |                                                                    |                                                               |     |                                                  |
| *Cabell Huntington Hospital                               | More trained staff                                                 | X                                                             |     | No need in past                                  |
| Colin Anderson Center,<br>St. Marys                       | More personnel, more & appropri<br>physical facilities             | X                                                             |     | No until recently,<br>program to be devel.       |
| Concord, Yellow Spring                                    | None                                                               |                                                               | X   |                                                  |
| Denmar, Hillsboro                                         | More staff trained in autism<br>and education                      | X                                                             |     | We do not serve communi<br>on out-patient basis  |
| Fairmont Emergency Hospital                               | N.A.                                                               | X                                                             |     |                                                  |
| *Highland Hosp. Children's Pav.<br>Charleston             | More, better trained staff                                         | X                                                             |     |                                                  |

## Survey Questions 19. and 20.

## Hospitals/Clinics (cont'd.), Agencies, Homes, Schools

| NAMES                                                     | 19. Resources & support needed<br>to serve autistic clients<br>Comments | 20. Facility an appropriate<br>placement for autistic persons |     | Comments                                |
|-----------------------------------------------------------|-------------------------------------------------------------------------|---------------------------------------------------------------|-----|-----------------------------------------|
|                                                           |                                                                         | No                                                            | Yes |                                         |
| Hopemont Hospital, Preston                                |                                                                         | X                                                             |     | Not currently                           |
| *Huntington Hospital, Psychia.D.                          |                                                                         |                                                               |     |                                         |
| *Huntington State Hospital                                |                                                                         |                                                               |     |                                         |
| *Greenbrier Community Center,<br>Lewisburg                | More training, more informat.                                           |                                                               |     |                                         |
| Lakin State Hospital, Lakin                               |                                                                         |                                                               |     |                                         |
| *Marshall Univ. Psa. Practice<br>Huntington               |                                                                         |                                                               |     |                                         |
| Pinecrest Hospital, Beckley                               |                                                                         | X                                                             |     | Not at present                          |
| Spencer Hospital, Spencer                                 |                                                                         |                                                               |     |                                         |
| *St. Mary's Hospital,<br>Huntington                       | N.A.                                                                    | N.A.                                                          |     |                                         |
| Welch Emergency Hospital, Welch                           | N.A.                                                                    |                                                               |     |                                         |
| Weston State Hospital, Weston                             |                                                                         |                                                               |     |                                         |
| *WVU Med. Ctr., Charleston,<br>Ped. Dept.                 | More tr. staff, more A clients                                          | X                                                             |     |                                         |
| *WVU Med. Ctr. Charleston,<br>Psychia. Dept.              | Nice housing facilities for<br>diagnosis                                | X                                                             |     |                                         |
| *WVU Med. Ctr., Morgantown,<br>Ped. Dept.                 |                                                                         |                                                               |     |                                         |
| *WVU Med. Ctr., Morgantown,<br>Psychia. Dept.             | Coordination with well-tr.<br>teachers in school system                 |                                                               | X   | Mostly for diagn.<br>work up            |
| AGENCIES                                                  |                                                                         |                                                               |     |                                         |
| *Center for Independent Living,<br>Huntington             | More trained staff                                                      | X                                                             |     | Not yet, as progr.<br>expands           |
| Cerebral Palsy Council, Cabell<br>County, Huntington      |                                                                         | X                                                             |     |                                         |
| *Children and Family Service<br>Association, Wheeling     |                                                                         | X                                                             |     | Only counseling of<br>families          |
| *Crippled Children, Dept. of Welf.<br>Huntington          | Different purpose of progr.                                             | X                                                             |     | Only if client has<br>add. med. problem |
| *Good Will Industries,<br>Huntington                      | Improved skills for higher<br>functioning                               | X                                                             |     | Only for evaluation<br>at present time  |
| Vocational Rehabilitation,<br>Institute                   | Possibly more trained person.                                           |                                                               | X   | In some cases                           |
| *WVARC, Parkersburg                                       |                                                                         |                                                               |     |                                         |
| WV Dept. of Welf., Div. of<br>Social Services, Charleston | More trained staff                                                      | X                                                             |     |                                         |
| HOMES                                                     |                                                                         |                                                               |     |                                         |
| Andrew S. Rowan Memorial Home,<br>Sweet Springs           |                                                                         |                                                               |     |                                         |
| Elkins Group Home, Elkins                                 | Training in autism                                                      |                                                               | X   |                                         |
| SCHOOLS                                                   |                                                                         |                                                               |     |                                         |
| WV School for the Deaf & Blind,<br>Romney                 | N.A.                                                                    | X                                                             |     |                                         |

SECTION FOUR



RECOMMENDATIONS\*

(By Topic)

| Service                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | Deadline               | Agency Responsible      | Branch of Gov't.      |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|-------------------------|-----------------------|
| I. Diagnosis                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | June 1983              | Health Education        | Executive Legislative |
| A. Establish a diagnostic center or diagnostic service (geographically and economically accessible to families) with appropriately trained staff.                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                        |                         |                       |
| II. Training (listed in order of priority)**                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                        |                         |                       |
| A. Establish an Autism Training Center, modelled on the one described in the WV autism education state plan.***                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | 4 months after passage | Board of Regents Health | Legislative Executive |
| B. Provide in-service training for all personnel in all government agencies who interact with autistic individuals or who supervise personnel.                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Apr. 1 1983            |                         | Legislative Executive |
| <p>*By unanimous consent, the Task Force did not rank these services (items I, II, III, etc.) in terms of priority. It was felt that, instead, a broad-front approach was needed for <u>all</u> services listed.</p> <p>**Within the service areas there was a strong consensus on need for and agreement on priorities.</p> <p>***This plan, completed in December 1981, was written by Autism Services Center under contract with the WV Department of Education and is entitled <u>Recommendations for the Delivery of Appropriate Educational Services to School-age West Virginians with Autism: A State Plan.</u></p> |                        |                         |                       |

RECOMMENDATIONS (continued)

| Service                                                                                                                                                          | Deadline                                           | Agency Responsible                         | Branch of Gov't. |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------|--------------------------------------------|------------------|
| III. Parent/Family Support Services (listed in order of priority)                                                                                                |                                                    |                                            |                  |
| A. Respite.                                                                                                                                                      | Jan. 1983                                          | Health Welfare                             |                  |
| B. Stipends for parents/families/guardians with autistic relative at home.                                                                                       | July 1983                                          | Health                                     | Legislative      |
| C. Chore services, homemaker services.                                                                                                                           | Jan. 1983                                          | Welfare                                    | Executive        |
| D. Training/Awareness                                                                                                                                            | Jan. 1983                                          | Health Education                           | Executive        |
| E. Accessible, free, appropriate advocacy and information available by telephone hotline.                                                                        | Jan. 1983                                          | Health                                     | Executive        |
| F. State support for statewide advocacy group (WVSAC).                                                                                                           | Jan. 1983                                          | Health Welfare<br>Voc. Rehab.<br>Education | Executive        |
| G. Appropriate Guardianship.                                                                                                                                     | Jan. 1983                                          | Health                                     | Executive        |
| H. Appropriate, equitable insurance standards (e.g., if a blind person's traveling companion is covered by insurance policy, so should be an autistic person's). | July 1983                                          | Insurance Commission                       | Legislative      |
| I. Sensitive, appropriate family counseling.                                                                                                                     | Jan. 1983                                          | Health                                     | Executive        |
| IV. Community Living Alternatives (listed in order of priority)                                                                                                  |                                                    |                                            |                  |
| A. Natural home.<br>(see Support Services, Items A - I)                                                                                                          | Jan. 1983                                          | Health                                     | Executive        |
| B. Group living.<br>(Medley Class members who are autistic and in institutions to be out, beginning Sept. 1983)                                                  | RFP out by 1/15/83;<br>Issue contract by July 1983 | Health Welfare                             | Executive        |
| 1. Staff-intensive programs (with appropriately trained staff).                                                                                                  | Service begin by Jan. 1984                         |                                            |                  |

RECOMMENDATIONS (continued)

| Service                                                                                                                                                                                                                                                                                    | Deadline                  | Agency Responsible                            | Branch of Gov't. |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------|-----------------------------------------------|------------------|
| Community Living Alternatives (continued)                                                                                                                                                                                                                                                  |                           |                                               |                  |
| <ul style="list-style-type: none"> <li>a. Appropriate respite for staff (to prevent burn-out).</li> <li>b. Competitive pay, taking into consideration "front-line combat" duty.</li> </ul>                                                                                                 |                           |                                               |                  |
| <ul style="list-style-type: none"> <li>C. Foster home.<br/>(Appropriate <u>mostly</u> for short-term respite.)</li> </ul>                                                                                                                                                                  | July 1982                 | Welfare                                       | Executive        |
| <ul style="list-style-type: none"> <li>D. Apartments (groups or individual).               <ul style="list-style-type: none"> <li>1. Intense supervision.</li> <li>2. Light supervision.</li> </ul> </li> </ul>                                                                            | Jan. 1984                 | Health                                        | Executive        |
| <ul style="list-style-type: none"> <li>V. Zoning<br/>(For same freedom to choose neighborhood as nonhandicapped citizens.)</li> </ul>                                                                                                                                                      | 1983 Legislative session. | City and county gov't.                        | Legislative      |
| <ul style="list-style-type: none"> <li>VI. Awareness<br/>(See Discussion of Recommendations)               <ul style="list-style-type: none"> <li>A. Among professionals.</li> <li>B. In agencies.</li> <li>C. Among legislators.</li> <li>E. Among general public.</li> </ul> </li> </ul> | Jan. 1983                 | Health<br>Education<br>Welfare<br>Voc. Rehab. | Executive        |
| <ul style="list-style-type: none"> <li>VII. Case Management<br/>Based on community services as described in the Medley Comprehensive Plan for <u>Community Based Services for DD Persons in WV, Final Report, October 1981.</u> (See Discussion of Recommendations)</li> </ul>             | Aug. 1, 1982              | Health                                        | Executive        |

## Discussion of Recommendations

(By Topic)

## Introduction

The Task Force, by unanimous consent, did not rank the recommendations. There was a strong consensus that work on all fronts needs to proceed with equal energy and speed. Because so few services are now provided, and because so little is yet generally known among most professionals and agencies, the interdependence of recommendations became apparent. The logic is circular and goes like this: Appropriate services (e.g. diagnosis, education, community living arrangements, family support service) will be inadequate-to-nonexistent until there is more training for professionals and service providers; training will not come about without special funds; special funds will not be appropriated until there is more awareness among professionals, legislators, and the general public. There will not be more awareness until there is more training.

Within the service areas there was a strong agreement on priorities.

In reviewing other state surveys, reports, and plans (see Attachment # 3 ), one finds a striking similarity of recommendations. When parents have strong input into the study, respite and community-based services usually surface as a major recommendation. Professionals want mostly in-service training.

The seven recommendations made by the Task Force cover services from birth to death. Because the West Virginia Department of Education



has recently (December 1981) received a detailed autism education plan (Sullivan and Rowe, 1981) based on a statewide survey of existing educational services and needs for school-age autistic children, the Task Force decided to enter its recommendation on education to conform with that of the autism education plan. There will, therefore, be only a limited discussion on the education item.

#### I. DIAGNOSIS

Establish a diagnostic center or diagnostic service, geographically and economically accessible to families, with appropriately trained and experienced staff.

A good pediatrician was unable to diagnose my son; we had to beg for the name of a consultant. A Board-certified psychiatrist was also unable to identify the problem, but he called two months later to say he'd spoken with Ruth Sullivan and he suggested an autism diagnosis.

By luck, an early education consultant came to my son's private kindergarten to evaluate a mentally retarded child. She took my son into behavior training. He spoke his first spontaneous, appropriate sentence six months into the program.

Parent from Charleston

### Discussion \*

Because autism is a relatively rare, still little-known disorder, and in addition, one about which there remains considerable mystery, few professionals feel comfortable making the diagnosis. Yet without proper identification, individuals with autism cannot hope to receive the highly specialized programs which are, for the most part, their only hope for staying out of state institutions.

Lack of appropriate diagnosis condemns autistic individuals to fitting into existing programs which are rarely geared— either by staffing or curriculum— to deal with the severe and unusual behavior and learning styles of autism. Most staff in most programs have had little or no experience (and even less training) with this group of developmentally disabled.

Without proper diagnosis there cannot ever be a reasonable count of how many autistic individuals there actually are in our state. A recent survey (Sullivan and Rowe, 1981) of West Virginia public schools revealed that of the state's total special education enrollment (13,080), only 76 (p. 16) were identified— far from the 986 the survey (p. 12) projected. Interestingly, of the 76, only eight were called autistic. Forty-six were called "autistic-like," probably reflecting the state of the art among diagnosticians who are not yet confident of their knowledge of autism. Thirty-two were in a combined category, for example "mentally retarded with autistic tendencies."

It is projected that 2,925 residents of West Virginia are autistic-like (see Attachment # 4 ), using the definition of the National Society for Autistic Children (see Appendix # 4 ). Yet the

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\* This material is excerpted and paraphrased from a recent discussion (Sullivan, 1982) of the need for diagnostic services in West Virginia.

identified individuals in our state number no more than 175—76 from the above-mentioned school survey, and 99 from the statewide survey of nonschool programs done for this project ("Opening Doors...").

Unless personnel dealing with these unusual human beings know what they are working with and that there is a body of technology available to ameliorate the symptoms of their unusual and profound handicap, individuals with autism will continue to "fall through the cracks" with cruel regularity. Without a useful child-count, school systems and other services cannot plan for better programs. Professional training schools in our universities will not be under pressure from the service agencies to adequately prepare personnel. Institutions of higher learning will not request the Board of Regents to establish new training programs. Legislators will not have pressure to appropriate funds. Unlike a Rube Goldberg design, there is yet no focal point at which to innervate the system to produce what is needed for autistic individuals— appropriate, accessible, timely services. Diagnosis is an important starting place.

There are probably fewer than five professionals in our state who have had some appropriate diagnostic experience (and who have sought additional information and training). Most West Virginia clinics, hospitals, and private practitioners are woefully uninformed about the syndrome of autism. Autism Services Center usually refers parents and others to out-of-state facilities, the closest of which is in Washington, D.C.

## II. TRAINING

A. Establish an Autism Training Center, based on the model described in the West Virginia autism education plan \* (see Attachment # 3).

### 1. Center Staff

This Training Center would have a highly skilled, interdisciplinary, appropriately experienced staff who would train professionals, parents, and others who are involved in the care and welfare of autistic individuals.

### 2. Trainees

Trainee Teams would come to the Center for a specified period (probably about three weeks).

3. The Trainee Teams would consist of an autistic student/client/ resident; his or her parent, when applicable; and a professional, preferably the one who had been working with him/her.

4. The training would be individualized and specific to the student/client/resident.

5. The Trainee Team would live at a special residence ("sheltered hotel"), with trained house parents, and go daily to the Center.

6. After the training, the Team would be offered intensive follow-along services via a hotline and/or on-site consultation.

B. Provide in-service training for all personnel in all government agencies who interact with autistic individuals.

1. Examples of agencies: state hospitals, community mental health centers, schools (including vocational education and adult

\* See Sullivan and Rowe, 1981.



education), health departments, vocational rehabilitation agencies, day-care centers, Head Start, Crippled Children's Services, emergency services (e.g. ambulance services, emergency room services), and police.

The summer my autistic son was nine, he was reluctantly allowed in a communications disorders class operated by the county school system. His regular-school-year teacher was busy in some other part of the building when I arrived with my son that first day.

An older woman was leading the singing of several smiling children with Down's Syndrome who were obediently sitting at a table. She said politely, "Miss \_\_\_ will be right back; just leave your son here," pointing to the table of singers. I was holding my extremely hyper-active son securely by one arm, not daring to let him go until there was a second adult in the room.

Seeing my hesitance, the woman said, "I've taught school for over 30 years, dear. Leave him. He'll be all right. Miss \_\_\_ will be here soon."

When she told me the third time about her 30 years' experience her tone implied, "You're just an overanxious mother," so I released the hold on my son and went home.

Within one-half hour the phone rang. It was the principal saying I was to come get my son immediately. The aide in the classroom couldn't manage him and had gone home with a headache.

Parent from Huntington

### Discussion

In response to our survey question about what additional resources or support agencies would need if they were willing to admit autistic individuals or increase the number of those they now serve, most agencies responded (see p.29 ) "more training." \*

Professionals not familiar with autism often find it hard to believe that they cannot successfully deal with this group of handicapped individuals. However, there is usually a total conversion to the need for more and specific training once they've encountered their first autistic student/client/resident/patient. This is not to say there are not gifted professionals who intuitively use their previous experience to arrive at useful and sound procedures to deal with the highly unusual behaviors and cognitive styles of individuals with autism. However, they, too (and certainly their autistic clients!), benefit from specific training. Without it even the most sensitive and resourceful professionals waste precious time "learning the ropes" at the autistic individual's expense.

Among the most common experiences of parents of autistic children (before the passage of P.L. 94-142 in 1975) was that of being told, "He doesn't fit our program." Untrained staff was usually the main reason the child could not be accommodated. Our survey of West Virginia facilities (see pp. 29-30 ) reflects the same reasons.

Untrained (in autism) psychologists often label autistic children "untestable." State institution personnel place autistic residents on back wards assigned to the "hopeless." Several

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\* This corroborates the replies on training gathered by the previously mentioned survey of educational needs in West Virginia (Sullivan & Rowe, 1981) where 77 % of the respondents indicated they would like more training.

years ago when a judge ordered the deinstitutionalization of school-age residents of Pennsylvania's Pennhurst State Hospital (Halderman vs Pennhurst State Hospital) , the staff was stymied at efforts to place the last eight— all of them autistic.

A teacher's ignorance stirred up a furor recently among knowledgeable professionals and parents of autistic children when the New York Times (1982) printed an anonymous first-person account (see Attachment #5) by a teacher with almost 20 years' experience who was assigned to an autism classroom. "They cannot learn," said the teacher— not "I cannot teach them." The onus is placed on the children. It is a case of "blaming the victim."

The Times letters-to-the-editor editor says there has been an unusually high response to the story— almost all taking issue with "Anonymous."

One educator who is also the parent of an autistic son replied (Isabel Schwartz, 1982):

(My) son... like a great number of children who have autism, is unmotivated to accomplish all or most of the things he can do. Given an option, he would rather "self-stimulate" and make noises. This is what he would do for the teacher in question, and unless she talked to me, or read previous records, she would have no idea that he could do anything other than what she was seeing.

(The anonymous teacher's statement) is made not from common sense but from ignorance.

One West Virginia county director of special education agreed to admit a three-year-old autistic boy to a public-school kindergarten class. (The age of mandated education for the handicapped, as for normal children, is five. Legislation for education under five is permissive.) She described the child's behavior as being "like an

animal." Recently, one year after the boy's admission, she visited the class. He sat when directed, followed instructions, responded to the teacher's requests. The county director was so moved by the dramatic progress he had made, "I cried," she said.

The discussion above has focused on school-age individuals, but it must be pointed out that because of the severe behavior problems of autistic individuals (especially those who do not have appropriate programs), most of them are seen by other community service agencies long before they start school. Also, during their school years (until age 23 in West Virginia) they need many services other than education. And, of course, after school-leaving age, they need appropriate services, such as job training, community living, and recreation.

Without appropriately trained staff, there is not much hope that individuals with autism will make the progress their potential promises.

### III. PARENT/FAMILY SUPPORT SERVICES (listed in order of priority)

Like autism study groups in other states, our Task Force ranked respite as the highest priority of family support. The reader will note that recommendations for services that would help to keep children at home were of the highest order.

#### A. Establish respite services

The Interim Autism Study published by the Texas Society for Autistic Citizens (1981) summarizes the need for respite:

Institutionalization of the autistic person may be avoided or deferred if necessary support services, external to the traditional residential placement system, are available in the community. One support service vital to the above goal is respite care of



sufficient quality and quantity to meet varying needs of clients and their besieged families (p. 113).

Of all the family services listed, none ranks higher than respite. Most families want to keep their child at home as long as possible, especially during the growing-up years. The highly unusual behavior of autistic individuals and the necessary intense, sustained vigilance of caretakers creates great stress in the families (especially in mothers, who are often like prisoners in their own homes). Compounding the problem is the reluctance and general unavailability of baby-sitters and other relief persons to care for autistic individuals. It is not at all unusual for extended family (grandparents, aunts, uncles) to withdraw from the "autistic family," further depriving them of a supporting network.

Parents of autistic teenagers commonly report that their child has never been invited to spend a night away from home or has never been invited to a party. The constant, unrelieved stress of living with an autistic child contributes to early institutionalization of some children. Marian K. DeMyer (1979) says

...parents who keep (autistic adolescents and adults) at home are exposed, in addition to other stresses, to perpetual parenthood of a child at a mental level of, say, 2 to 3 years of age. No major developmental change is in sight and there is no light at the end of the tunnel (p. 227).

Following are some examples of problems faced almost daily by many parents of autistic children who are "runners."

When Kristen was six years old, she used every unsupervised minute to run away. Once when Kristen sneaked out the front door fifty Boy Scouts, a whole student dormitory, four policemen, and the principal of the high school where I taught were looking for her. She was found on the second floor of an apartment building, leaning over the railing, fearless and smiling. She loved all the attention she received when she was found; she did not seem the least bit frightened to have been away from our home.

Huntington mother

On June 16, 1981, three-year-old Matthew slipped outside our house. Because he often hides in closets and under things, we didn't miss him right away. After searching the house we started to look for him outside. We alerted neighbors and began searching the creeks and hillsides. Matt's father drove along the road.

We found Matt running down the road wearing just a Pampers. Putting the story together later, we learned he had run past three adults, a car had pulled over for him, and he outran the children who tried to stop him. One child did stop Matt, but could not hold him. From what we could determine, Matt ran one mile in about twenty minutes.

Wayne County mother

When George, 3½, disappeared one day, we immediately looked in all the usual places, but found his tracks on a dirt road that followed a stream and ended at a very busy street. As I raised my eyes I saw a car of gray-haired ladies abruptly slowing down to avoid hitting George. He did not budge, but when the car completely stopped, he matter-of-factly climbed on the bumper, over the hood, up the windshield. By the time I reached him he was sitting on top of the car, from which I snatched him and mumbled something like "Thank you" to the stunned ladies.

A father

### Kinds of Respite

1. In-home, so main caregivers (parents, foster parents, guardians, etc.) can go out for short periods without the autistic child.

2. Out-of-home, so parents and families can have a block of time without struggle on such occasions as bringing home a new baby, giving a party for a normal sibling, having friends in to dinner, or just being quietly at home. Most parents of autistic children do not know this kind of relief, even when (in some cases, especially when) the autistic individual is no longer a child.

Parents find it hard to understand the logic of the

state's willingness to spend \$27,375 a year\* per resident in a state institution,\*\* while failing to appropriate and budget a relatively small amount of funds on respite services which are essential for avoiding-- or at least delaying-- institutionalization.

B. There should be stipends for parents/families/guardians with an autistic relative at home.

There was strong agreement among Task Force members that families who keep their autistic children at home need financial support.

Clara Claiborne Park, in her book You Are Not Alone (1976), gives this exhortation to families:

Feel no shame when you make your relative's and your family's needs known to your community. If we want to think dollars and cents instead of human misery, you are saving them money in the long run... (H)elping him and you at home is not only more humane but cheaper. One reason it's cheaper is that you, the patient's family, are bearing much of the economic, social, and emotional cost. By trying to help your relative, you are helping your community. You have a right to expect your community to help you. (Emphasis added.) (p. 139)

Parents of autistic children have unusual expenses which often do not decrease, as in normal families, as the child gets older. Here are some parent comments.

\*Personal communication, December 3, 1981, with representative of Tom Stalek's office at Colin Anderson Center.

\*\* Out-of-state residential placement for autistic individuals costs between \$30,000 and \$60,000+ per year.



This past winter Daniel, now 15, ripped and ruined three overcoats, tore out the lavatory in our newly remodeled bathroom, and punched holes in the living room wall.

Mother from a rural county

Michael would sometimes run into the kitchen, throw open the refrigerator door, grab and squeeze the butter, eat part of it and smear the rest on himself and the floor in a matter of seconds.

One summer he yanked down the living room drapes, rod and all, upset all the furniture, tore off his clothes, used the whole house as a bathroom.

He also ripped our clothes.

Parkersburg mother

Joseph, between ages 4 and 8, put deep marks on every side of every door frame in two houses (one we'd just built) with ball point pens, which no amount of ingenuity in hiding or concealing could keep him from discovering. Our books, piano, furniture and ceilings also did not escape his deft artwork. We couldn't sell the house when we moved.

Huntington mother

There are now at least ten states which have legislated family stipends (see Attachment #6 ). By October 1981 Idaho had become the eighth state to enact a family support/cash subsidy program.

So far in 1982 four more states (Nevada, Nebraska, Rhode Island, and Connecticut) have passed legislation providing financial aid to certain families who care for their disabled relative at home or whose family member could, under the act, come home from an institution (Up Front, 1982, p. 5).

The financial aid may be spent for such items as attendant or respite care, home health aides, homemaker services, transportation, counseling, training, diagnostic services, special equipment, home renovation and repairs.

The direct cash assistance legislation was first passed by Minnesota in 1975. The states have a variety of criteria for families' eligibility, usually based on greatest degree of need (for example, a single parent). Some states (e.g. Idaho and Florida) have no financial criteria for eligibility. The amount of the subsidy averages about \$ 250 per month, with waivers for extra need. Florida sets a maximum of \$ 680 per month. Idaho's grant to a family may not exceed 33 % of the current average institutional cost\* (Bates, 1981).

With such a stipend, families could purchase services not now available. For instance, a community with 20 families needing

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\* If West Virginia had a family subsidy plan like Idaho's, such a ceiling (33 % ) would be approximately \$9,200 per year, based on Colin Anderson's current average cost per patient.

respite will not be long in developing such services if there are funds immediately available from the families to pay for them.

#### C. Chore services, homemaker services

Family stipends could help buy these services, which give relief to caretakers (usually mothers or other women) and help prevent burnout. These services should also be available from the Department of Welfare.

#### D. Training/Awareness

##### 1. Training

Most parents are eager to learn ways to successfully deal with their child's isolation, resistance to learning, and severely disruptive behavior. So important is parent training that the authors of P.L. 94-142 and its regulations wrote it into the Act as a right.

Caution must be exercised, however, that an already overburdened parent is not loaded down with more "homework" than she/he can manage without more stress. Enthusiastic professionals sometimes underestimate the social, physical, and emotional cost of the extra time and energy parents spend at home on professional/program-directed activities.

##### 2. Awareness

A large number of autistic children/adults are first diagnosed by their parents, sometimes after reading a newspaper or magazine article, seeing a television show, or talking to a friend who took a course in child psychology or special education. Awareness that such a disorder exists and information about its salient features are crucial for identification and timely amelioration.

Until nonspeaking Patrick was a mid-teenager I thought he was retarded (albeit "odd-retarded"). Professionals who saw him said he was. In 1972 I read some of the National Society for Autistic Children's literature and began to suspect Patrick might be autistic. I went to their annual meeting that year, heard their speakers, spoke to many parents, and came home knowing that we had been operating under the wrong diagnosis. Because of what I learned at the conference I began to understand things Patrick had been trying to tell us for so many years.

He would expertly place his record player needle on the record, exactly where the song was saying, for example, "I'm leaving on a jet plane, don't know when I'll be back again." Over and over he'd play it. Finally I said, "Patrick, are you unhappy with me because I left you to go to the conference?" He looked at me (rare) and pushed me out of his room. Since then we have had numerous "conversations" through his record player. He and a friend have cut records of various expressions of speech and we are truly communicating for the first time in his life.

What fun for us and for him. But I wouldn't have understood if I hadn't gone to the NSAC conference.

Excerpted and paraphrased from a mother's letter



E. Accessible, free, appropriate advocacy and information available by telephone hotline.

Families of autistic children are terribly alone, for the most part, and need sensitive, experienced counsel. Information is crucial, but it is not enough. Our parents can rarely be referred to an existing, appropriate program for their child unless they are willing to move. They— more than the parents of children with most other handicapping conditions— need to be systems-changers.

These parents, and the professionals who work with them and their children, need direction and persistent encouragement. At Autism Services Center in Huntington, a fairly large percentage of time is spent doing actual case management with parents and professionals who call in.

Funds for such a hotline should come from the agencies which are serving, most likely to serve, or which should be serving autistic individuals. These are the Departments of Health (especially the Developmental Disabilities Planning Council and Behavioral Health Services), Education, Welfare, and Vocational Rehabilitation.

F. Continued support for the statewide advocacy group—the West Virginia Chapter of the National Society for Autistic Children.

WVSAC's Annual Meeting and Conference each fall is a vehicle for West Virginia parents and professionals to meet, hear from, and interact with those individuals who shape the development of the field, whose research and work are part of the force which brought, and is bringing, autism to the attention of professional

disciplines, service agencies, researchers in other fields, government, and the community at large.

Held each year on the campus of one of the state's universities or colleges, the conference also gives an opportunity to professionals and students to see a group of diagnosed autistic individuals within a range of ages. Parents are encouraged to bring their children with them. Expenses are paid for those that do. Elaborate and careful child care is planned so that parents will be free of child-care responsibilities during the conference hours. University students from special education, psychology, hearing and speech, nursing, medicine, physical education (adaptive), counseling and music volunteer their services (some for credit). When conferences were held at Marshall University, students under faculty supervision did psychological and auditory testing on some of the autistic individuals. Since there are no autism training programs\* at state institutions of higher education, these conferences supply excellent opportunities for students, faculty, other professionals, and parents.

The 1980 Conference, held at Marshall, cosponsored by seven university departments and six state agencies, drew over 300 people from seven states during the 2½ days. It is a major autism training activity in the state and deserves continued support.

#### G. Appropriate Guardianship

Parents need much good information and counseling in this area. They worry about what will happen to their child when they

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\* Since 1980 there has been a week-long, residential summer autism program at Marshall University which is an introduction to autism.

are gone. Sometimes parents have spent 20 to 30 years trying to get appropriate services and wonder who will persist in looking after the child's welfare when they are no longer around.

The Task Force assigned the responsibility for developing and refining guardianship information and activities to the Department of Health, since it is this agency which often is ultimately the caretaker of the autistic individual when all his/her support persons are no longer available.

#### H. Appropriate, equitable insurance standards

Insurance companies are, generally, much more familiar with and responsive to the needs of the physically handicapped or medically needy. Parents of autistic individuals and others with mental handicaps need insurance coverage for other services— like psychotherapy/counseling and attendant care.

Frank Warren, Executive Director of the National Society for Autistic Children, points out, in an article by Behavior Today (1981)

...that improved knowledge of the characteristics of autism among insurance-company policy enforcers is needed...In fact, (Warren) has aided parents by contacting insurance companies in specific cases (p.7).

While our son was in play therapy he had an educational evaluation. Our insurance company at first refused to pay. We spent several months getting letters of support from professionals who know about autism and who confirmed our position that education is crucial and is "therapy." After 18 months, during which my husband visited the New York headquarters office several

times, we were finally reimbursed for 50% of the costs.

Mother from St. Albans

# I. Sensitive, appropriate family counseling

No subject brings on stronger feeling among parents than the way others, especially professionals, treat them and their children. Marion DeMyer speaks of the problem (1979):

(P)arents have enormous adjustments to make as they learn about autism in general and their own child in particular. If they are to find the best in education and therapy that their community has to offer, they must generally become diplomatic evaluators of educators, physicians, psychologists, and social workers (p. 173).

It is parents who are the lifelong advocates of their children. They need good information upon which to make decisions which profoundly affect their and their child's lives. Yet in the DeMyer study 48% of the parents reported that "professionals failed to communicate adequately with them" (p. 178). In an earlier study (Salvagne et al., 1974), parents wanted to know much more from the professionals than they got— even if it was bad news.

DeMyer's study (1979) also reports:

—Unfortunately, in about 57% of cases parents found nothing positive to say about their experiences with the "experts," and 28% had a mixture of good and bad things to say, leaving only 15% with strongly positive feelings (p. 177).

—(P)arents named three times as many complaints about professionals as admired qualities (p. 177).

—Professionals were seen as being too taciturn: i.e. "One thing I've noticed about doctors is they don't talk to you—they'll hardly tell you anything at all" (p. 178).



—Not listening, not believing, or belittling what the parent said caused much anger and even bitterness (p. 179).

—Parents were especially upset if a diagnosis was made on the basis of a short interview without any special tests (p. 179).

—If a child was in the hospital for several days...complaints were frequent that parents learned little or nothing of "what doctors found after all those days...." (p. 179).

One of the few examples the study reports of positive feeling toward professionals was

"The man at the Child Guidance Clinic has given us very simple and forthright explanations. You ask him a question and he takes time to explain things. It makes me feel more relaxed" (p. 177).

This DeMyer study was conducted from a hospital setting, so most responses were to reactions to medical personnel. Parents also deal with psychologists; teachers; dentists; mental health, social, and welfare workers; Social Security personnel, etc.

And we know that there are many good, warm, caring professionals who truly empathize with the families. They sometimes become the leaders in autism among their peers because they do understand and are determined to help.

DeMyer asks herself, "Are we as unclear, taciturn, and unhelpful as the parents see us?" (1981).

The answer is a mixture of yes and no. Part of the problem lies in the condition itself and in the level of knowledge of child mental health practitioners about autism (p. 181).

#### IV. COMMUNITY LIVING ALTERNATIVES (listed in order of priority)

When school-leaving age\* arrives (and younger for some autistic

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\* Age 23 for West Virginians who are handicapped.

individuals who cannot be managed at home, for whatever reason), there is a rising anxiety among families and professionals about "What happens next?" There are now no community living arrangements in the entire state for individuals labeled autistic.

There is still some question about the costs of institutions when compared to community; however, if the full array of appropriate services are available in both settings, evidence seems to indicate that community living is only slightly cheaper (Jones & Jones, 1976; Mayeda & Wai, 1976; and Fredericks et al., 1980). In West Virginia there is no state institution with such "full array of appropriate services" for autistic (and most other DD) children. What is gained, says Fredericks,

is a more humane environment and better opportunities for further placement in an even less restrictive (and less costly) setting, such as foster homes or an independent living facility (p. 462).

All three studies found, however, that the least expensive care, by far, occurs when the client lives at home with natural parents.

But a recently published study on "Cost Effectiveness of the Group Home" by Templeman et al. (1982), from Teaching Research in Monmouth, Oregon, reports that

there is solid evidence for the cost effectiveness of these types of group homes for children. Coupling cost-effectiveness data with data relative to skills acquisition and behavior improvement...a strong case emerges for the group home as a comprehensively effective alternative to large institutions (p. 16).

"These...group homes" refers to transitional, training group homes. Children (ages 7-17) came from their natural homes and from state institutions. After the group home training (average stay was 15½ months), 33% of the children went back to their natural families. Foster family placements were made by 62% of the group. Both parents and foster parents also received training.

These figures are encouraging, luring, but, upon inquiry, we were told that the one autistic child in the study, after two foster homes in one year, was the only child who had to be returned to the institution (Fay, 1982). This finding lends support to the consensus of the Task Force (p. 49) that foster home placement is almost never an appropriate placement for autistic individuals.

#### A. Natural home

Because it is least costly, even when providing family stipends,\* it would seem state agencies and legislatures would see the logic in encouraging families to keep their handicapped child at home as long as possible. Unfortunately, for severely handicapped individuals such as those with autism, there are ordinarily only two alternatives for living arrangements—home or a state institution. Knowing the conditions in most state facilities, parents usually opt for keeping their child at home, sometimes enduring stress almost beyond imagination. We've known families who have kept their destructive, runaway, unmanageable ten-year-old boy in a cage in their kitchen. The family's philosophy: "If he must live in a cage, at least it will

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\* The most generous family stipend we found was Idaho's, which would waive the \$250/month ceiling, and in cases of extraordinary need could go as high as 33% of that state's institutional costs (see Idaho, Attachment # 6).

be where he can see us and we can love him." Another family put iron bars on "Billy's apartment," the basement of their home with windows on one side. They installed an iron-barred gate on the steps leading up to the kitchen. Another mother put off desperately needed surgery for 18 months until she could finally get her son into a facility that was relatively safe (but with no program).

With a family support system,\* including respite and other services listed (pp. 58 - 65 ), and with appropriate community services, most families would be able to keep their children at home longer. The more severely handicapped the child, the earlier institutionalization is likely to occur, especially when the handicap is behaviorally manifested, as in autism, and especially if support services are not readily available.

#### B. Group living

##### Discussion

"I'm not against getting these people out of institutions, I just don't think they belong in this neighborhood" (Stroh, 1981) is the common protest when group homes move into a neighborhood. It happens so often that it has been given a name-- the NIMBY Syndrome ("Not In My Back Yard").

In spite of resistance and "recognizing the compelling need to find satisfactory homes for their deinstitutionalized patients, 21 states have statutes declaring that small group residences be considered single-family dwellings for zoning purposes (Peirce, 1981, p. 4c).

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\* Connecticut calls their's "Parent Deinstitutionalization Subsidy Aid Program."



### 1. Establish group home for autistic individuals

This recommendation generated a great deal of discussion from the Task Force. Where should it be located? For what degree of severity (high- or low-functioning?) How many residents to a house? Qualifications of staff? Who will pay for the costs? When should it be ready? Which agency should be responsible for developing it?

It was recommended that the Departments of Health and Welfare be accountable for this project.

#### a. Deadlines

The timing should be as follows: the Request for Proposals to be out by January 15, 1983; the contract issued by July, 1983; the service to begin by January, 1984.

Medley class members who are autistic and in institutions are to be out beginning September, 1983.

#### b. Program recommendations

1. The group home is to be staff-intensive with appropriately trained staff.
2. Adequate respite is to be provided to staff to prevent burnout.
3. There should be competitive pay, taking into account the "front-line combat" duty.

### 2. Apartment living

Some advantages to apartment projects are 1) avoiding the zoning problems, 2) no "up front" money as in new construction or

buying older property, 3) less trouble with neighbors, and 4) no long-term commitment to site.

Even severely handicapped persons can live in an apartment setting, provided there is appropriate supervision. The intensity of staff support can vary. For the higher-functioning autistic individuals, light supervision (from helping resident buy groceries, manage money, organize some recreational activities, to supervising housekeeping, etc.) would probably suffice. Apartment supervisors could manage several apartments while living (in the same building, or down the hall) separately from the autistic individuals. Or a supervisor could live with two or three autistic residents in the same apartment. There would have to be some outside program (school, training, sheltered workshop, or job) during the day.

For the more severely involved autistic individuals, there would have to be a great deal more supervision, possibly even round-the-clock staff presence.

The Maryland Society for Autistic Adults and Children now operates such an apartment living project in Montgomery County, outside Washington, D.C.

#### C. Foster home placements

Members of the Task Force were in agreement that foster homes were not likely to be a good placement for most autistic individuals, except, perhaps, in short-term placements, or for the more mildly handicapped. Based on information gleaned (by one of the authors of this document--R.C.S.) from experiences of such foster

families around the United States, foster parents burn out for the same reasons natural families do-- but almost always much sooner.

There would need to be adequate training and support services for them, too, as described on p. 58.

#### V. ZONING

The discussion on zoning was placed under the Group Homes heading, since it is so intimately related.

The Task Force recommends that statutory restrictions on placement of group homes be lifted and that legislation for this change be sought for the 1983 legislative assembly.

#### VI. AWARENESS

##### A. Among professionals

As discussed earlier, until professionals are generally informed about autism, services will not be adequate. Beginning at the professional school in universities, students need to have a good introduction to autism and its ramifications. There is the problem in our state of no specific training in autism. Even information which now exists on library shelves is a problem. The Texas study (Texas Society for Autistic Citizens, 1981) found that a

(r)evue of a limited number of college texts in special education and speech and hearing disorders reveals that information about autism is neglected or outdated (p. 100).

It is imperative that erroneous information about parents, which fills the pages of the autism literature before 1970 (and, unfortunately, even some since) be eliminated. Sullivan (1976) writes:

(Pejorative writing of professionals against parents) is especially true of the behavior disorders where, until recently, parents (especially mothers) were almost universally blamed for their child's etiology. No parents have been more maligned by professionals than those of autistic children (p. 39).

The battle of psychogenic etiology in autism has now been won, largely. It is of mostly historic interest at this time when new research clearly points to biogenic clues. However, professionals working with parents of older children need to know that there still remains in some of these parents a wariness of professionals. One has only to read some of the 10<sup>+</sup>-year-old literature to understand why.

Here is an example (Vetter, 1969):

Family life is usually of a cold, formal type and the child has received very little fondling, cuddling, or warm and genuine expressions of parental affection. The mother's behavior is mechanical and does not convey love. When a child with early autism is brought to the clinic, his parents readily volunteer the opinion that he is severely retarded and should therefore be "put away" (p. 81).

#### B. Awareness in agencies

In preparing their report, The Endless Quest: The Autistic and Their Families, the authors write (New York Commission on Quality of Care for the Mentally Disabled, 1981):

During this process (interviews, reading personal accounts) Commission staff became very close to these parents. Indeed it was difficult not to identify with their needs and concerns. As for their demands, they seemed small in comparison to the damages wreaked upon them by an inadequate, and often insensitive, service delivery system (p. 13).



Further on the commission authors write about parents' experience with agencies:

Most parents of autistic children soon become alienated from the so-called "helping" professionals. They recount how one educational and mental hygiene agency after another sent them away because their child simply did not fit into a program (p. 15).

Agencies need to make a planned effort to acquaint themselves with the problems of the autistic individual and his/her family. Workshops, seminars, in-service training, meetings with parent groups, reading the literature would be excellent ways to begin.

Parents, and the professionals who work closely with them, are often surprised to learn how little the agency personnel know, not only about autism, but about the lack of services in their own community for this population of handicapped people. They casually refer parents ("treat by referral") to mental health centers, to directors of special education, to the divisions of vocational rehabilitation, seemingly without the slightest understanding that autism services at those places are as nonexistent as at theirs. Parents get the runaround at almost every turn.

One totally exhausted, physically ailing, single mother had reached the point of total burnout and called the local community mental health center for a screening so her child could be placed in an institution (at least temporarily). The daughter is sometimes physically aggressive toward her mother and both had been put out

on a strange street far from home by a taxi driver when the child "acted up." When the mother said she couldn't come in a cab without another adult along, the MHC worker indicated that was the mother's problem. The worker was irritated when the mother hung up on her and complained to several of her colleagues about the "uncooperative" client.

Information and understanding of autistic parents' situation would have prevented overwhelming stress to this mother, and temporary stress to this worker.

### C. Awareness among legislators

Ultimately, it is legislators who make most new (especially if expensive) programs a reality. But they need to understand special problems and believe that suggested solutions are the right ones.

Legislatures and elected officials are sensitive to the state of the state and most of them want their state to be perceived as up-to-date and intelligently and humanely administered. They need good information, persistently and opportunistically presented, upon which to make decisions.

It is especially helpful if the agencies of government and consumers agree on what is needed. It was for this reason that the Task Force for the "Opening Doors..." project was composed of consumers (parents of autistic children), agency representatives, and legislators.

Legislators create awareness, since the law also instructs. Senator Jacob Javits of New York, for instance, was mainly responsible for the inclusion of a bill of rights in the federal Developmental Disabilities Act of 1975. An immense amount of credit for P.L. 94-142

(a Magna Carta for the handicapped) goes to West Virginia's U.S. Senator Jennings Randolph, who for many years chaired the U.S. Senate Subcommittee on the Handicapped. The law responds to and refines communal conscience.

Because parents are "pure advocates," they need encouragement and support in working with the legislature.

#### D. Awareness among the general public

The problems of families with autistic children are awesome, but the condition itself would be so much easier to live with if society did not create further burdens. Autism is manifested by aberrant behavior, and since society has rigid norms for what it considers proper, it punishes those who deviate, even if that deviation is not harmful.

Many parents, particularly mothers, give up outings if they have to take their autistic child along. One mother says about her daughter (Morton, 1978):

I took her shopping with me only if I felt up to looking groomed, cheerful, competent, and in command of any situation, so that when she bellowed and stamped with joy as she always did when we walked through the supermarket door, people who stared could quickly surmise that I would handle the situation, quiet my strange child, and get on with my shopping (p. 144).

Lorna Wing, an authority on autism, a psychiatrist, and mother of an autistic daughter, wrote (1972):

An autistic child who is given to screaming is not inhibited by being in a public place, and will scream as loud and long in the street as at home. He may take things off shop counters,

run into the back premises of shops, or enter the homes of complete strangers. He has no idea that it is not done to take off one's clothing in public and will happily disrobe to sit in an inviting puddle of rainwater, if so inclined. He will rub his face against a fur coat, and look right through the person wearing it if she speaks to him (p. 27).

They will also reach over in church and stroke a stranger's bald spot, help themselves to food on the plates of the diners at the next table in a restaurant, slink on their bellies under the seats the length of an airliner or a movie theater.

I was determined to take my mute 10-year-old son to church. In the middle of the sermon he spoke, loud and clear, his first word: "S—t!"

Anonymous mother

Our son, age 9, needed dental work, so I brought him to the dentist who had seen several of our other children. I thought it would be helpful to explain that he was autistic, but the dentist reacted as though I'd put a rattlesnake in his chair. We never went back.

A Huntington mother

We decided to take 11-year-old Winston for a field day to do some of his favorite things: eat out, shop for food, take a trip to the mall.

When we went to the bank, I left him in the car with my 23-year-old niece and her mother. He became abusive and the fracas got loud. Someone called the police. As I came out of the bank, it



was a few moments before I realized that the commotion around my car was the police arresting my niece— for child abuse. Her mother couldn't understand why her daughter was being arrested. There were excited verbal exchanges and a fight. She was arrested, too.

When my eyes frantically searched for Winston, I saw him sitting quietly in the back of the car, looking like an angel.

A grandmother from Fairmont

Whenever I go out with my son I feel as though I need to explain his behavior to people he shocks or offends. Sometimes if they seem too hostile or too involved in lecturing me ("What that boy needs is a good smack on his bottom" after he'd opened a lady's purse and helped himself to some chewing gum), I don't try. But I now carry NSAC brochures explaining autism in my purse and hand them out, then leave quickly as I can.

A Cabell County mother

An informed public would be much more accommodating and less traumatizing to families. Recent media attention to autism has already helped.

Again, state support to the WVSAC to continue their aware-

ness campaign is an important way to improve community attitudes. One of WSAC's outstanding services is a lending library\* which can be reached through the mails.

Agencies, especially Health and Education, could be effective in developing and widely distributing good information about autism.

#### VII. CASE MANAGEMENT

Though listed last (remember the Task Force did not rank the seven services), the need for case management is immediate and crucial. Because most services\*\* are not available, the case manager for persons with autism will need to be familiar with autism and the special problems of the children/adults and their families. This person must know what is needed and how to develop appropriate services in a community where there are now none. A great deal of precious time will be lost if the case manager must do a lot of on-the-job learning. It is important that this person be knowledgeable about current standards of practice and successful programs in other states, and have sufficient experience in working with community agencies to be an effective manager.

Because of the likelihood that such a person as case manager cannot be found in each region of the state, and without whom autistic individuals and their families are much less likely to get what they need, we are therefore recommending that case management for autistic persons be available in a single office with statewide outreach.

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\* Contact Marie Decker, 1006 Sand Hill Drive, St. Albans, WV 25177. Tel.: 304-727-9948.

\*\* Education being the only notable exception; however, even those mandated services are often not appropriate.

This recommendation would comply with Section III of the DD state plan by Irwin Schpok (Program Research Associates, 1981), which discusses statewide provisions of services that are

- 1) unavailable in the regions,
- 2) of low enough demand or so specialized as to prohibit efficient delivery at the regional level....(p. 31)

If the autism caseload is left to the regional case managers only, without experienced back-up support, it is likely that services to autistic clients will suffer for the same reasons as before. These are: inordinate amount of time spent on one case, to the detriment of others; slow to no progress in obtaining services from community agencies; severe, intense, and often emergency needs that have no or an unsatisfactory solution; immense frustration and psychological drain of working with this caseload, especially if the case manager has no previous experience. These are conditions for burnout, desirable for neither manager nor client.

We further recommend that the Medley Management Team\* or its designee contract with an agency to serve as the autism case manager. When autism cases are assigned to the regional case manager, the autism agency would be requested to give assistance, or to take total responsibility for the case, until the client's needs are stabilized and no longer require the special services of the autism case manager. At this time the case would be turned back to the regional case manager, with the autism case manager available for consultation or sporadic temporary assistance, as needed.

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\* Made up of representatives of the Departments of Health, Education, Welfare, and Vocational Rehabilitation who work as a committee to carry out provisions of the Medley Consent Decree.

SECTION FIVE



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## SUCCESS!

*Editor's Note: Again it is our pleasure to present readers with a SUCCESS! story, further documentation that people with autism can reach their individual goals when given the opportunity! Congratulations Joe, and very best wishes for the future!*

# Hard-won graduation marks man's defeat of special handicap

When Joseph Sullivan was 6 years old, his mother wrote in her journal, "I wonder if he'll ever be able to answer a question."

Joseph graduated from Huntington (WV) High School recently, an accomplishment "we never dreamed possible just a few years ago," said Ruth Sullivan.

Joseph is autistic. He can multiply two-, three- and four-digit figures in his head before you have time to push "equals" on a calculator. He has perfect pitch. Given your date of birth - say, November 7, 1957 - that fast he tells you, "I think it was a Thursday." And he's right.

"Joe has a fantastic memory," said Mrs. Sullivan. "He has a mind like a computer."

Unchanging situations are a snap for the 21-year old man. But the social amenities most people his age have are foreign to people like Joe.

Joe has come a long way, his mother said, from a non-speaking child "for whom two words a day was a big deal" to a young man who will interview for a job next week.

During Joe's early childhood, Mrs. Sullivan said, "My highest hope was that he could be involved in a conversation of any kind."

Mrs. Sullivan and her husband William came to Huntington from New York in 1968 when Joe was 8 years old and very hard to manage. They moved to the South Side at a time when Joe had a compulsion to burst into neighboring homes, unwanted and unannounced.

One disgruntled neighbor threatened to sue, but two retired teachers - Lucy and Virginia Lewis - taught him not to come visiting unless he was invited. As a reward, they held cookie parties once a week for Joe.

When Joe reached the 10th grade in the Cabell County school system, Mrs. Sullivan learned his teacher would be a young woman just out of Marshall University.

"I can tell you, I was not happy," Mrs. Sullivan recalled. "A brand new teacher with a fresh degree coming to teach my son? As it turned out, she was one of the best things that happened to him. She's gifted like Annie Sullivan."

Melanie Butler, 25, resource room teacher at Huntington High School, laughed. "I bet she was just as apprehensive of me as I was of Joseph," she said.



Joseph Sullivan with his teacher Melanie Butler, at graduation.

She had a master's degree in behavior disorders, but had no training with autistic children before working with Joseph.

"I was scared to death," she said.

Mrs. Butler inadvertently put Joseph in some regular classes, or "mainstreamed" him, and it worked.

She taught him for three years and said Joseph is in some ways far superior to the other graduates at Huntington High.

His math and vocabulary skills are excellent, Mrs. Butler said, but his social skills and reading comprehension are probably lower than average.

Mrs. Butler saw Joseph with the other seniors at a luncheon yesterday and observed, "Even though Joseph is the best known kid in school, there wasn't one person he could call a friend."

The Sullivans had a party for Joseph last night, and all the people who took a special interest in him were invited.

"We're having a party because we think this is a special occasion in Joe's life," Mrs. Sullivan said.

She and her husband have worked for years for laws that mandate education for people like Joe - laws that were passed and are now endangered by the current administration.

Federal guidelines stipulate that Joe is entitled to education until he is 23 years

old. Mrs. Sullivan said he will enroll at the Huntington Business School in the fall.

By the time he is 23, she said she hopes her son will have some job experience and training so that he will be an income-producing citizen.

Joseph's graduation is "a magnificent accomplishment," Frank Warren, executive director of the National Society for Autistic Children said. He and his mother are excellent examples of people who go in with the attitude that "by George, the system is going to provide as it is required by law."

*Editor's Note: The above was taken from an article by Patty Rhule that appeared in THE HERALD DISPATCH, May 29, 1981. As most of our readers know, Ruth Sullivan is a past president of NSAC and is a member of NSAC's Honorary Board.*

## A Reminder

All chapters are reminded that the deadline for award nominees is April 15. Please get your packet ready - 5 copies of the material - and send to Martha Tucker, Awards Committee Chair, 12830 Danube, Florissant, MO 63033.



Funds Spent on Autism  
by the  
West Virginia Developmental Disabilities Planning Council  
1971 - 1982

|                                                                                               |                      |
|-----------------------------------------------------------------------------------------------|----------------------|
| WVSAC Annual Meetings<br>1976-1981<br>(approximately \$1000 each year)                        | \$ 6,000             |
| 1980 Special Training at WVSAC Fall Meeting                                                   | \$ 7,100             |
| 1981 Special grant by DDPC for the<br>development of a comprehensive state<br>plan for autism | \$17,200             |
|                                                                                               | <hr/>                |
|                                                                                               | Total \$30,300       |
|                                                                                               | (.16% of DDPC funds) |
| <br>Total Income of the DDPC*<br>(1971 - 1982)                                                | <br>\$18,616,141     |
| Federal                                                                                       | \$ 8,216,141         |
| State & Local Match                                                                           | <u>\$10,400,000</u>  |
|                                                                                               | \$18,616,141         |

\*Information furnished by Richard Kelly, Program Specialist.  
DDPC, June 15, 1982.

## OTHER STATE AUTISM STUDIES AND PLANS: SUMMARIES

The purpose of this section is to briefly review existing published or planned studies or state program descriptions with a focus on objectives, methodology and outcome, and thereby to provide a background for current national trends in statewide service delivery systems.

California

At this time, in California, a Study to Identify the Population Considered Developmentally Disabled, Including Autistic, According to the Federal Definition in PL 95-602 is in process. On November 23, 1981 the California Health and Welfare Agency issued a request for proposals to study P.L. 95-602 and assess the impact on existing programs in California if the federal definition is applied to state service systems.

Colorado

A Needs Assessment of the Autistic Population in Colorado was completed in February 1981, a joint project of the Colorado chapter of the National Society for Autistic Children and the Colorado Developmental Disabilities Council. The project's central purpose was to identify the numbers of autistic people in Colorado, with emphasis on identifying "nondiagnosed" citizens. The study is comprehensive and detailed. Assessments of the existing service delivery system and barriers to service are also included, as are general recommendations for programs.

The needs assessment was followed up by The Comprehensive Plan for the Colorado Autism Project: A Center for Training and Treatment: ACTT which appeared in August 1981. Developed by the Colorado Chapter of NSAC with a grant from the Colorado DD council under P.L. 95-602, this plan provides specific program goals and objectives for residential services, recreation, respite care and training. Guidelines for the establishment of the Chestor Home are presented, as are detailed plans for respite care, a Saturday recreation program and training for students, parents and teachers.

### Connecticut

As of this writing, a Connecticut Task Force on Autism has been in existence for approximately two years. Under the auspices of the Community Services Division of the Department of Mental Retardation, the Task Force coordinates autism service delivery throughout the state. Although the Task Force recently published a compendium of autism services in Connecticut, according to chair Dorothy Avis, no statewide studies or plans are targeted.\*

### Florida

The Autism Study Group for the Florida Developmental Disabilities Council issued Autism: A Study of Service Needs in April 1978. This study examines the status of existing services for autistic individuals in Florida and reviews public school programs. A service continuum for autism is described, based primarily on general treatment-theory considerations. The group presents a number of broad, long-term goals and recommendations for state legislative action (i.e. funding) on autism programs. Emphasis is placed on utilizing existing services and changes that can be effected without new expense are noted.

### Illinois\*\*

The Illinois Autism Study was jointly sponsored by the Illinois Department of Specialized Education Services and the Governor's Planning Council on Developmental Disabilities. An Autism Advisory Committee was employed to provide input regarding recommended courses of action and to review study materials. The methodology utilized was limited to informal polling rather than more formal statistical methods of investigation. The study includes description of the existing system, and identification of service deficits and gaps. Among the most useful outcomes were provisions for a comprehensive model continuum of services and recommendations for implementation of a wide range of services.

\*Dorothy Avis, Director of Program Services, CT Dept. of Mental Retardation, in telephone conversation, June 10, 1982.

\*\*Bauserman & Williams, A Study of Statewide Services for Persons with Autism in Virginia, 1981, p.8.

Indiana

The Indiana legislature has directed the Indiana Commission on Autism to oversee the development of a Comprehensive Plan for services for autistic persons, to be completed by October 1, 1982. This plan will be developed cooperatively by the Indiana Departments of Public Instruction, Mental Health and Public Welfare, the Rehabilitation Services Board, the Indiana Commission on Autism and other appropriate agencies. Emphasis is on designing specific programs to meet the needs of citizens of all ages with autism.\*

Developing Appropriate Educational Programs for Autistic Children, a resource manual published in November 1981 by the Division of Special Education of the Indiana Department of Public Instruction, "is intended to provide special educators, administrators, and parents with direction so that educational services for children with autism are appropriately related to the needs of these children."

Iowa \*\*

Autism: Assessment of Needs within Heartland Education Agency is the title of an in-depth study completed recently (1979) in an eight county area in Iowa. The educational needs of children who exhibited characteristics of autism were studied. Trained observers completed detailed behavioral observations, interviews with teachers, reviews of student records, and behavior and language questionnaires. Children were assigned to one of four groups descriptive of the degree and kind of handicap and the most appropriate service delivery option was determined. The distribution of children by chronological age, county or residence and communication level was determined. The study suggested the need for the development of separate classes, special programming and staff inservice training.

Kansas

A set of recommendations for the education of autistic and autistic-like children and youth was drafted by the Kansas Society for Autistic Children in 1981. The final plan is not complete.

\*Indiana Division on DD, News Notes, Vol. 3, Summer 1981, p. 11.

\*\*Bauserman & Williams, 1981 p. 9.



### Louisiana

As of this writing, resolutions to establish a legislative study committee on autism have passed both houses of the Louisiana legislature. Final passage is expected; the committee will begin meeting in the interim session.

### Maryland - Baltimore County

Programming for Students with Autistic-like Behavior: A Report to the Baltimore County Public Schools was published in June 1980 by Behavior Service Consultants, under contract to the Baltimore County School System. The study reviews various approaches to educating autistic and autistic-like children, researches existing needs and services in Baltimore County and presents detailed recommendations for the development of appropriate programs within the school system. As a result of this study the Baltimore County system elected to adopt the Judevine techniques of teaching autistic children. Federal discretionary funds (under P.L. 94-142) were used to train 11 teachers at Judevine and to consult with that center regarding program specifics. According to Joyce Reier of the Baltimore County School System, the new program is very successful: "Economically, it was the most sound thing we could do."\*

### Michigan

In January 1977 the Michigan Department of Education approved a "Position Paper on Educational Services for Autistic Children." This brief document was completed at the urging of parent groups; it represents their and the state's general, philosophical commitment to educating autistic children. No statewide study of educational services for the autistic population is available or planned.\*\*

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\*Joyce Reier, Office of Special Education, Towson, MD.  
In a telephone conversation, October 13, 1981.

\*\*Norman Francis, Special Education Services, Michigan Department of Education. In a telephone conversation, October 13, 1981

Nebraska\*

The Nebraska project consists of a series of modules being developed through the joint cooperation of the Nebraska chapter of the National Society for Autistic Children, the Meyer Children's Rehabilitation Institute and the State of Nebraska Developmental Disabilities Unit. The basis of the study was a survey sent to over 240 parents and professionals in an effort to determine who were the most difficult to serve, barriers to services, causes of institutionalization, and needed services. The outcome was the publication of four pamphlets entitled "Recognizing Autism," "The Needs of Autistic Children and Their Families," "Guidelines to Establish Adequate Service Programs for Autistic Persons," and "Current and Future Directions in Services for Autistic Citizens." The emphasis of the program is on the development of family-based and community-based services for the multiply-handicapped, severely disabled children and adults.

New Jersey

The Report of the New Jersey State Task Force on Autism (January 1982), prepared for the New Jersey Department of Human Services, Division of Mental Retardation and Division of Youth and Family Services, outlines general considerations and assumptions in autism service delivery, critically evaluates the current state of autism services in New Jersey, and makes recommendations for planned improvement of services. Recommendations are coded to indicate priority rank, practicality (i.e. ease of implementation and cost effectiveness) and whether they are primarily administrative in nature. The Task Force's major recommendation provides for the creation of an Office/Division of Developmental Disabilities and the formation of Regional Centers on Autism.

The bulk of New Jersey's report is devoted to the recommendations and their rationale. It is not clear precisely what methodology was employed to evaluate services and assess needs, although a substantial amount of "background material" was provided

\*Bauserman & Williams, 1981, p. 9.

to the Task Force by various state agencies and professionals in autism.

#### New York

The Endless Quest: The Autistic and Their Families, a report by the New York State Commission on Quality of Care for the Mentally Disabled, was issued in August 1981. The commission surveyed the autistic population of New York and the existing services available to them. Unmet needs are charted and barriers to meeting those needs described. The report presents eight recommendations for service delivery, specifying the New York Office of Developmental Disabilities and Mental Retardation as the "lead agency."

#### North Carolina \*

The North Carolina program for persons with autism, Division TEACCH (Treatment and Education of Autistic, psychotic and Communications handicapped Children), is one of the best known programs nationally as well as the source of numerous published articles. The program was organized to provide a comprehensive range of services individualized according to the needs of each child and his or her family. Since being mandated by the North Carolina state legislature in 1972, it has been a separate Division within the Department of Psychiatry of the School of Medicine at the University of North Carolina. The current TEACCH program represents the expansion and further development of an earlier research project which was designed to demonstrate the feasibility of training parents to function as co-therapists with their own psychotic children. The program was the first one to be endorsed by NSAC.

#### South Carolina

According to the South Carolina Society for Autistic Children, "a task force to study appropriate educational programming needs and opportunities

\*Bauserman & Williams, 1981, p. 8.



for older autistic pupils in local Education Agencies and State Operated programs has been appointed by the State Superintendent of Education. Members of the task force include Coordinators of Programs for the Handicapped and teachers of handicapped pupils from local school districts, Personnel (sic) from the Autistic Program operated by the South Carolina Dept. of Mental Health, and parent representatives from the S.C. Society for Autistic Children."\*

The first meeting of the task force was held in November 1981, the second in December. Additional information was unavailable to this project by deadline.

#### Tennessee\*\*

The Project to Assess Services to Tennessee Autistic Children (Project ASTAC) based its study upon a questionnaire designed to assess the perceived need for services as well as the current availability and appropriateness of the services. Of 107 respondents, the majority were professionals in the field of autism. The outcome of the study was a final report which described the characteristics of autistic, autistic-like and related communications handicapped persons, existing services, and needs. Recommendations for families and professionals who work with persons with autism, including implementation strategies, emphasized family involvement in the service delivery system.

#### Texas

The Interim Autism Study: August 1981 by the Texas Society for Autistic Citizens represents a series of reports and testimony generated over a two-year period through a grant from the Texas Developmental Disabilities Program. It is proposed as a source document for the SCR 100 (Texas Senate Concurrent Resolution #100) Joint Interim Committee on the Needs of Autistic Citizens. The publication includes general theoretical and statistical in-

\*South Carolina Society for Autistic Children, News letter, Vol. II, No. 6, Dec. 1981, p. 4.

\*\*Bauserman & Williams, 1981, pp. 8 - 9.



formation on autism, reports from a variety of autism projects in the state of Texas, discussion of relevant legislation, plus a section entitled "Issues in Autism Services" which offers recommendations for action on research, public and professional awareness, early diagnosis, prenatal care, preschool education, parent training, school-age education, personnel, availability of programs, professional training, vocational education, consultation, residential services, and respite. The recommendations, while specific, are not detailed (i.e. costs, salaries, particular personnel qualifications and time lines are referred to only generally). A fairly extensive bibliography and appendices are provided.

#### Virginia

Autism in Virginia: A Statewide Study was funded by the Developmental Disabilities Unit of the Department of Mental Health and Mental Retardation of the Commonwealth of Virginia and conducted by the Grafton School and the School for Contemporary Education. It required one and one-half years to complete. This formal, comprehensive research study includes a literature review, a recommended definition of autism, an enumeration and description of autistic people in Virginia, a description of current services and an evaluation of those services, and recommendations for service delivery. The recommendations are specific but not detailed. They cover the continuum of services for autistic citizens, including educational training and treatment services. The Virginia plan, with its extensive appendices and bibliography, is useful as a reference work.

#### West Virginia

Autism Services Center, under contract to the West Virginia Department of Education, Division of Special Education, published Recommendations for the Delivery of Appropriate Educational Services to School-age West Virginians with Autism: A State Plan in December 1981. The recommendations are based largely on a 5-month study of the state-of-the-art in autism in West Virginia which included, but was not limited to: 1.) a statewide survey of current

services and needs in the county public schools; 2.) needs as expressed by the West Virginia Society for Autistic Children; 3.) site visits to major educational programs in other parts of the country; 4.) consultation with nationally recognized experts in the education of autistic people; 5.) identification of the school-age autistic population in West Virginia and projections based on a statewide survey. The recommendations address twin, equally weighted priorities: appropriate educational programs for autistic students and appropriate training for education personnel. A major recommendation -- to establish and develop an Autism Training Center -- is analyzed in detail, including costs, salaries, qualifications of personnel, time lines, and specifications for facilities. The Center would operate with a highly skilled, interdisciplinary, appropriately experienced staff who would train teachers, parents and others important to the autistic student's education (e.g., school psychologists, teacher aides). During the three-week training course the Trainee Team (student, parent, professional) would live at a special residence with trained house-parents and go daily to the Center. After the Team has returned to its community, the Center would offer intensive follow-along services via a hotline and/or on-site consultation. (An Autism Training Center Bill is before the West Virginia legislature.)

#### Summary

The state plans and studies vary considerably in terms of focus and depth. All plans address education to some extent. Emphasis seems to be on the "continuum of services" for autistic people, with education a significant segment of the continuum. In many instances the "plans" are actually needs assessments which recommend that autism task forces or similar committees be formed for the purpose of developing specific action plans. Most of the recommendations presented address specific needs, but are expressed in general terms. Colorado and West Virginia, however, offer very detailed recommendations.

The state plans are consistent in their adherence

to the NSAC-sanctioned definition of autism. Also, the training and treatment techniques espoused are quite similar to one another. One general consensus of these studies is that autism should be designated a separate category of developmental disability.

Projections: School-age Autistic Children in WV\*

TABLE I

(calculations rounded off to nearest whole numbers)

| <u>AGES</u>   | <u>Population - WV</u> | <u>0.04% autistic</u> | <u>0.15% autistic/-like</u> |
|---------------|------------------------|-----------------------|-----------------------------|
| all           | 1,949,644              | 780                   | 2,925                       |
| under 5       | 145,583                | 58                    | 218                         |
| 5 to 9        | 152,802                | 61                    | 229                         |
| 10 to 14      | 157,489                | 63                    | 236                         |
| 15 to 19      | 174,204                | 70                    | 261                         |
| 20 to 24      | 172,688                | 69                    | 259                         |
| 25 to 29      | 160,954                | 64                    | 241                         |
| under 5 to 24 | 802,766                | 321                   | 1,204                       |
| 5 to 24       | 657,183                | 263                   | 986                         |

The WVDH estimates (1978-1979) and projections for the developmentally disabled population--based on WV population of 1,836,699--indicate that the autistic population of WV is about 755 people, out of a total DD population of 81,549. WVDH estimates that the school-age (5 to 23) autistic population is 242.

Lindberg (1976) broke down the DD population as follows:

|                   |       |
|-------------------|-------|
| Mentally Retarded | 73.0% |
| Downs Syndrome    | 8.7%  |
| Epilepsy          | 28.7% |
| Cerebral Palsy    | 9.5%  |
| Autism            | 0.8%  |
| Multi-handicapped | 8.4%  |

Lindberg's analysis is based on an autism incidence rate of 4 in 10,000.

The actual service picture for school-age autistic persons in West Virginia is rather more difficult to present. In part, this is because autistic children are often "hidden" in categories such as behavior disorders, emotionally disturbed, and mentally retarded. The 1979-1980 and 1980-1981 Enrollment and Financial Reports from the Division of Special Education do not include autism as a separate category. Indeed, there is no mention of autism in either report.

\*excerpted from Sullivan, R. & Rowe, L., 1981, pp. 12 - 15.



In West Virginia's public school enrollment, 13,080 pupils, or 3.4%, are enrolled as special education students (September, 1980 enrollment figures).<sup>\*</sup> According to Rosalind Glick, Coordinator for Behavior Disorders in the Office of Special Education, of this number, 18 are classified as autistic and 42 as autistic-like. Four autistic students are currently on out-of-state placement. See Table II.

TABLE II

Autistic and Autistic-like Individuals in WV Public Schools

|                                              |           |
|----------------------------------------------|-----------|
| Total number of autistic individuals served: | <u>18</u> |
| In Behavioral Disorder classrooms:           | 9         |
| In Mentally Retarded classrooms:             | 4         |
| Other:                                       | 5         |

|                                                   |           |
|---------------------------------------------------|-----------|
| Total number of autistic-like individuals served: | <u>42</u> |
| In Behavioral Disorders classrooms:               | 8         |
| In Mentally Retarded classrooms:                  | 9         |
| Other:                                            | 25        |

|                                                                              |          |
|------------------------------------------------------------------------------|----------|
| Total number of autistic individuals currently<br>on out-of-state placement: | <u>4</u> |
|------------------------------------------------------------------------------|----------|

(quoted from letter from Rosalind Glick, received July 17, 1981)

Forty-two (76.4%) of the fifty-five county special education services responded to a questionnaire from ASC (see table). The counties were asked to identify the number of autistic and/or autistic-like students being served by their school systems. Those students identified included children in pre-school handicapped programs and in one case, in a vocational rehabilitation program. Ages given ranged from 3 to 21. Eight (8) children were listed as autistic, 46 as autistic-like, and 22 were identified in a combined category. The total reported number served, 76, is higher by 16 than the number reported in the service picture provided by the Behavior Disorders Division of the West Virginia Office of Special Education.

There are several possible reasons for this discrepancy (which may be even

<sup>\*</sup>From Gerald S. Harper, Statistician, WV Dept. of Education, Bureau of Finance and Administration, July 30, 1981.

greater, given that 14 counties did not respond to the questionnaire):

1. Some of the children may not be counted as autistic by the state. Respondents indicated that these students had a "principal" diagnosis of MR, for instance, but had "autistic characteristics". This is an example of the "hidden" autistic student; 2. Some of the children are newly identified or perhaps have not yet been formally diagnosed; 3. The state office did not receive complete information from the public schools.

Counting autistic school-age children in West Virginia presents several problems. First, autism is a low-incidence disorder. The entire population of West Virginia would probably have to be surveyed because sampling procedures do not seem to generate enough cases to provide reliable data (Lindberg, 1976, p. 42). Second, many autistic children have been misdiagnosed or placed in inappropriate settings and classified with other disabilities. Third, people with developmental disabilities do not appear to be distributed randomly or uniformly throughout the population of West Virginia (Lindberg, 1976, p. 42). Whether this is true of autism is unclear. Nevertheless, given the rural character of the state, it is highly likely that many autistic children in West Virginia are undiagnosed and unserved.

It is more difficult to count the autistic and autistic-like school-age population served outside the school system in West Virginia. A survey being conducted by ASC\* (under contract to the West Virginia Department of Health) for the project, "Opening Doors for West Virginians with Autism," reveals that 13 state hospitals and agencies now serve autistic people. In most cases, ages and numbers of those serviced were not given. Some autistic clients are concurrently served by public schools, others are residents of state institutions and are usually classified under a different disability.

The Three-Year (1978-1981) Report of West Virginia Advocates for the Developmentally Disabled (WVADD) (Mason, 1981) states that WVADD handled 1010 cases, 36% were mental retardation, 6% epilepsy, 7% cerebral palsy, and 2% autism. By contrast, the general DD population is comprised of 73% mentally retarded, 28.7% epilepsy, 9.5% cerebral palsy, and 0.8% autism (Lindberg, 1976). All disabilities were underrepresented in terms of WVADD cases EXCEPT autism, which was "overrepresented" by as much as 250% (using the 4 in

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\*Autism Services Center

10,000 incidence rate). Even if a higher incidence rate is employed and possible duplications of cases and inaccurate diagnoses are accounted for, the number of autistic cases handled by WVADD remains significantly greater, proportionately, than the number of autistic people in the DD population as a whole. This discrepancy suggests that autistic people and their families have a greater need for advocacy services than other DD people and/or that they have fewer other resources to tap in our state.

It is also interesting to note that a majority (56%) of WVADD's cases (of all disabilities) involved the school-age population (Mason, 1981). Based on ASC's survey of the West Virginia public schools and health institutions, and upon knowledge of the autistic population through advocacy activities and through liaison with WVSAC, it can be roughly estimated that there are now approximately 100 school-age West Virginians served and/or identified at some level as autistic or autistic-like. In other words, only about 10% of the projected autistic and autistic-like school-age population (986 people, ages 5 to 24 - see Table I) is recognized as autistic.



"This Is the Way She Is":Anonymous Letter and Responses

## 'This Is the Way She Is'

**T**HIS year, for the first time in almost two decades of teaching, I am teaching a class of six autistic children. There is a full-time aide with me who works very hard and is caring and concerned about the children. She has one quality you don't learn in school and can't get from books. It is the invaluable quality of good common sense.

I sometimes doubt that the children are autistic. When I questioned the psychologist about one youngster, she answered: "I never said that he was autistic, only autistic-like." Then she added, "He can also be placed in this class because his parents do not object to the label of autism."

One youngster will soon be 11 years old. He has a mental age of one year and seven months. He has learned absolutely nothing, not even where his nose is.

Another youngster, who is nearly 12 years old, has a mental age of a 3-year-old. With one hand he twists paper in front of his face. When I reach over to remove the paper and engage him in another activity, he becomes very aggressive and hostile. This is another child who has never said one word.

There is a 13-year-old boy who whispers when you speak to him and walks on tiptoe in a circle. He has the habit of endlessly flicking his index finger. After he

flicks his index finger, he presses down on the table with the heel of his hand and then smooths the table out. This is known in educational jargon as self-stimulating behavior.

One girl is echolalic. Whatever I say she repeats. As my aide says, "This is the way she is and this is the way she'll always be." There is quite a bit of truth in this statement. She has not changed at all.

One youngster has learned a great deal. She is the exception, and she alone has made the days meaningful. When she is absent, I'm devastated and depressed.

All of these children receive 30 minutes of individualized speech therapy a day.

I'll be teaching tomorrow, and the day after tomorrow, the same thing that I taught yesterday and the day before yesterday.

I have no qualms about explaining the true nature of my work to anyone who inquires about it. If I were to be completely honest, I'd have to say that I am the highest-priced baby sitter in the world.

What other country would take an 11-year-old child who has the mental age of a one-year-and-seven-month-old baby, label him as autistic, put him in a classroom to be taught when he cannot learn, and then pay the teacher over \$20,000 a year?

Put very simply, I don't consider the services that I render in that classroom, with the exception of one child, to be educational.

The author requested anonymity.

NYTIMES: 5-2-82

L.I. section



# LONG ISLAND OPINION

THE NEW YORK TIMES, SUNDAY, MAY 16, 1982

## 'This Is the Way She Is': Parents and Educators Comment

**A**S an educator and the parent of a child having autism, it is with a deep sense of sorrow, frustration and anger that I respond to "This Is the Way She Is," by an anonymous teacher of autistic children (Opinion Page, May 7).

The sorrow is for a dedicated teacher who is upset by her inability to "reach" and change her students; the frustration is because teachers and aides are still being sent into classrooms totally unprepared and untrained to work with children who have autism, and the anger is because a teacher, in her total ignorance of how to deal with her class, has managed to cast aspersions on the ability of autistic children to learn, and to substantially denigrate the work of both professionals and parents who have proven again and again that children with autism can and do achieve.

My son is 13½, a similar age to the students in the class described by the anonymous teacher, and is also being taught in a class of six students who are autistic. He is called "autistic" not because the label has either positive or negative connotations, but because it describes his etiology and functioning. He is severely impaired

places him squarely in the severely retarded range.

Would you expect such a child to read, add, subtract, multiply, divide, type, operate a computer, take piano lessons, roller skate, ride a bicycle, act in a play, do the laundry, set the table and be bar mitzvahed? My son does and has done all of the above. The bar mitzvah, I might add, was done entirely in Hebrew with no steps skipped.

If these achievements sound impressive for a person whose I.Q. score characterizes him as being severely retarded, it is only because I.Q. scores and their mental age equivalents are not accurate measures of what an autistic person can achieve. More important is finding an area of strength that will motivate the child to achieve, and then working with methods that will encourage him to do so.

It is in this area that the anonymous teacher would fail with my son. He, like a great number of children who have autism, is unmotivated to accomplish all or most of the things that he can do. Given an option, he would rather "self-stimulate" and make noises. This is what he would do for the teacher in question, and unless she talked to me, or read previous records, she would have no idea that he could do anything other than what she was seeing.

It takes training to know how to intervene with a student such as my son so that he will do the tasks he is capable of doing. This teacher has not been

addition, my husband and I as parents were fortunate to have had the help of professionals at the Sagamore Children's Center who believed that "parents are partners" and taught us techniques of handling and teaching our son when he was young. I should add that similar training is available at this time for parents of children enrolled at the Suffolk Child Development Center, which has campuses in Smithtown and Stony Brook.

I have been active in the Nassau/Suffolk Chapter of the National Society for Autistic Children for eight years and have met many families with autistic children as well as the children themselves. I do not know of one of these children who has not made considerable progress. Our chapter's number is listed under "Autism, Autistic Children" in both the Nassau and Suffolk telephone books. Many people find it and call.

"This is the way she is and this is the way she'll always be" is a statement made not from common sense, but from ignorance. I invite this teacher and her aide to Great Neck on June 18 for an evening of entertainment and education that will include a slide show about what children with autism can do, and will have at least one such child entertain.

Further information about this event can be obtained by calling the number of the Nassau/Suffolk Chapter of the National Society for Autistic Children.

Isabel Schwartz

## One Must Start By Caring'

I am responding to the anonymous "This is the Way She Is."

I write because I am startled and even angered by the insensitivity in regard to the human needs of the autistic children with whom you work; in regard to the destructiveness of your comments, which undermine the struggles of beleaguered parents who have fought for schooling for their children and who still continue to fight as budgets are cut.

As a school psychologist involved with a wonderful Queens Board of Education program for the elementary-age autistic child, I have not only observed changes in many of the children, but I have observed:

Teachers who do not give up.

Teachers who find excitement in a minor change.

Teachers who have literally cried with joy when a youngster has blossomed enough to move to a less restrictive program.

If a child does not speak, the teachers learn "signing" as a way to approach him. They seek our help in various ways — all on behalf of "their" children.

I do understand how difficult it is for you to cope with simple repetitive behavior; but you are responsible for

There are no miracles, but one must start by caring.

SYLVIA F. EISENSON  
Flushing

## A Special Sense Of Mission'

The demands upon teachers involved in the training of the autistic child are profound. The rewards, monetary and personal are small, insufficient, but exist for some. Sadly, the anonymous Long Island teacher has found little gratification and meaning in her work.

Fortunately, for these children and their parents, there are still teachers for whom she is not a voice. They bring to this special work a sense of mission, empathy. They'd be outraged if considered "high-priced baby sitters."

We who live and work with multiply handicapped children learn a very difficult but important lesson. We often cannot expect them to help us feel personally or professionally validated. Of course, when change occurs in response to one's efforts, it feels so good, feeds one's narcissism, is proof of merit and worthiness. However, for some, like this teacher, its absence is devastating. It becomes our responsibility to locate meaning and value in

After 20 years of teaching, one wonders why this teacher finds herself bewildered and impotent in this special milieu of overwhelming need. No doubt the tasks are repetitive and change minuscule, if at all apparent. Her boredom and devaluation are symptomatic of the insidious burn-out that plagues many of our most essential and demanding professions.

Finally, we must also question what alternatives exist for the 11-year-old, who with a mental age of one year and seven months cannot find his way. When parents of children such as this make broad personal and family sacrifices to keep them from warehousing in institutional settings, such views as represented by this teacher shamefully add ammunition to the bureaucratic bullies of the "New Federalism."

DIANE EATON  
(Parent of two special children,  
social worker)  
Woodmere

## A 'Minute Step' Can Increase Joy

"This is the Way She Is" reflects a level of depression, despair and negativism that clearly marks the anonymous author as unfit to teach special-education children.

For the last seven years, my wife and I have watched our now 8-year-old autistic son slowly and painfully acquire the abilities necessary to enjoy life and become part of the community. Where once he was mute, he now speaks. Where once he lacked the most basic self-care skills, he now has become relatively independent. Where once he isolated himself, he now responds socially.

Perhaps all of these skills are marginal compared with the normal child, but we have been thrilled to see how the appearance of each one has made him a happier and fuller individual, with more hope for the future.

To us, it is clear that his classroom teachers have been the most significant

and effective members of the team required to achieve this progress. We, often discouraged ourselves, have been continually supported by their patience, skill, commitment and, most of all, their enthusiasm and positiveness, often in the face of depressingly low salaries and working conditions.

These teachers recognize that the concept of mental age, nebulous even with normal children, has no valid applicability whatsoever to the low-functioning developmentally disabled child. Rather, they focus on and extract whatever potentials these children have, knowing that even the most minute step forward can produce immeasurable increases in the joy of life for these children.

ALAN D. KARASIK  
Syosset

## 'All Can Be Taught To Communicate'

"This is the way she is and this is the way she'll always be" is true for the young autistic child if she continues to be educated by those unfamiliar with techniques proven to be successful in the education of the autistic. Scholarly journals such as the Journal of Autism and Developmental Disorders publish research studies demonstrating the success of structured and consistent behavioral approaches to the education of the autistic.

The anonymous teacher identified a major deficit area in her pupils: communication. There is, however, a wealth of data that demonstrates that even the most disabled autistic child can make progress.

All autistic children can be taught to communicate. While some achieve a high degree of verbal ability, others must rely upon nonverbal forms of communication such as sign language and communication boards.

Autistic children have abilities as well as disabilities. Unfortunately the disabilities frequently associated with autism, as the anonymous teacher describes, could lead an untrained person to overlook the real or potential abilities of these youngsters.

What should not be overlooked is the plight of the teacher in this classroom. Teachers of the autistic must be trained in those educational techniques that have been proven successful. Unfortunately for teacher and pupil alike, teachers unfamiliar with autism are regularly assigned to work with these severely disabled children.

Autistic children have the potential to learn. The realization of this potential depends on their being taught by teachers committed and trained to develop this potential to the fullest. This may be "the way she is"; it need not be the way "she'll always be."

MARGARET RAUSTIALA  
Assistant Director  
for Downstate Coordination  
New York State Society  
for Autistic Children  
New York

## Saving Families From Disintegration

I, too, am a teacher of the autistic. However, in contrast with Anonymous, I am unconcerned with labels. There are few autistic children who exhibit all of the classic characteristics. Children so labeled may be severely impaired or may exhibit few characteristics. It is unimportant.

My job is to find the ways and means to teach these children skills—self-help, communicative, motor and academic. In addition, using behavioral techniques, I remediate maladaptive behavior. In the 13 years I've been teaching, I have rarely found a youngster who could not be helped.

It is true, progress may be slow; also true — much effort is involved. But the children do learn, and many have been saved from being institutionalized. Furthermore, through parent training, families have learned to deal with their disruptive and difficult children. In this way family units have been saved from disintegration.

Had I and others like me expressed the negative views of Anonymous, these gains could never have been made. I am certainly not a baby sitter. I am an experienced professional educator who is enormously proud to be able to teach the "unteachable."

DORRIN C. CARLTON  
Suffolk Child Development Center  
Smithtown

## Interns Suggested As Class Aides

This is in reply to the anonymous teacher of autistic youngsters:

As a psychotherapist as well as mother of an autistic son, two things stood out for me in your article: about one autistic youngster who has made progress, you wrote, "When she's absent, I'm devastated and depressed." Any teacher, or other helping professional, whose own emotional state is dependent upon a patient or student needs to either develop greater inner resources and professionalism, or another career.

The second comment is about your practical aide who said, about the echolalic girl, "This is the way she is and this is the way she always will be." I agree with you that common sense in working with people — autistic or otherwise — is an important attribute. But so is inspiration.

Your present situation sounds totally discouraging, yet it could be enormously rewarding. With your employer's approval, you might contact some special-education departments and inquire about interns who might be thrilled to come into your class as aides — people who are studying to enter this field and need to intern for their degrees. It is possible you could get four interns; then the children in your class could have a one-to-one teacher ratio, it wouldn't cost a cent, and some real progress might be made.

PHYLLIS TERRI GOLD  
Co-founder and former officer  
The National Society  
for Autistic Children  
East Norport

## 'First, Acknowledge The Potential'

After our initial anger had subsided upon reading "This is the Way She Is," we felt it necessary to respond on behalf of autistic students and their many dedicated and skilled teachers. As educators of handicapped children, as well as teacher trainers, we have evidenced actual and documented educational gains in autistic students.

When describing the ineffectiveness of classroom instruction, the author may have been, in reality, commenting upon his/her limited abilities as a teacher. By stating that these students "cannot learn," the author placed responsibility for successful instruction squarely on the students' shoulders. This is unfair to handicapped learners as well as being in direct opposition to current special-education theory and practice.

Appropriate and thorough assessment would have led to the development of meaningful and achievable objectives. Further, appropriate systematic instruction would have demonstrated the attainability of these objectives.

DIANNE E. BIRKELL  
Assistant Professor  
JOEL E. MITTLER  
Assistant Professor  
Department of Special Education  
and Reading  
C. W. Post Center



## STATE FAMILY SUBSIDY/SUPPORT PROGRAMS\*

At present ten states have enacted family support/cash subsidy programs. These programs include: 1.) economic incentives to adoptive parents of difficult-to-place children; 2.) direct subsidies to families for the costs of caring for the developmentally disabled person in the home; 3.) technical assistance to families; 4.) respite care; and 5.) training to families with institutionalized members. Most states have found these programs to be significantly more cost effective than institutional placement. Marion Bates of the Wisconsin Developmental Disabilities Council staff has observed that, since their inceptions, none of the programs' budgets have been cut -- a testimony to their cost effectiveness as perceived by legislators.\*\*

Connecticut

The Parent Deinstitutionalization Subsidy Aid Pilot Program is administered by the Department of Human Resources. Aid is in the form of cash subsidies. Eligible applicants are natural parents of physically handicapped or developmentally disabled children who are in institutions, in order to enable those parents to maintain their handicapped children at home. Children must be under 18 or, if enrolled full-time in a school, college or training program, under 21. Families must not exceed prescribed income ceiling/size ratios. Per client expense limit is \$2,000 in one year. A home social study plan will be developed for and with qualifying families, which they must follow to receive aid. Connecticut has appropriated \$20,000 for this program in FY 1982.

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\*The information in this section is derived largely from a report by Marion Bates, "State Family Support/Cash Subsidy Programs", issued by the Wisconsin Council on Developmental Disabilities, Madison, WI, November 1981.

\*\*Marion Bates, Wisconsin Council on Developmental Disabilities. In a telephone conversation, June 11, 1982.



### Florida

The Family Placement Program is administered by the Department of Health and Rehabilitative Services, Developmental Disabilities Program Office. Aid is in the form of cash subsidies. There are no age limits or financial criteria. Priority is given to clients with developmental disabilities and an individual habilitation plan must document goals which, if not met, would require residential placement of the client. Eligible services include, but are not limited to, room and board, medical expenses, babysitting, transportation, parent training, and special clothing. Per client/family expense limits are based on client needs only. The current range of payments is \$30 - \$680 per month. \$150,000 plus an increase for inflation has been appropriated for FY 1981-82.

### Idaho

The Developmental Disabilities In-Home Financial Assistance Act is funded by the Idaho Developmental Disabilities Council and administered by the Department of Health and Welfare. Aid is in the form of cash grants. Parents of institutionalized children who will return them to their home and parents of children for whom institutionalization may be imminent are given priority. Eligible clients are persons 21 years of age or younger with developmental disabilities. Parents must participate in the development and implementation of an individual habilitation plan for the child. Some of the services assistance funds may be used for are diagnostic and evaluative procedures, child care, housing modifications, family training, medical care, respite care, recreational services, and transportation. Financial Assistance may not exceed \$250 a month per child (the limit may be waived, but no grant may exceed 33% of the current average institutional costs). \$45,000 was appropriated for the first year, which began October 1, 1981.

Michigan

The Family Support/Subsidy Program, administered by the Department of Mental Health, was established to maintain substantially handicapped children in their own communities and whenever possible in their own homes. Five programs are set up in conjunction with community mental health boards. Eligible clients are severely and profoundly mentally retarded children under age 18 who return to their homes from state facilities and severely multiply impaired and severely mentally impaired children residing in the community. There are no financial criteria. Services provided include special equipment, medical expenses, child care, diagnostic assessments, educational and training programs, and family support. The monthly ceiling for payments is \$300 per family. \$632,000 has been appropriated for FY 1981-1982.

Minnesota

The Department of Public Welfare, Mental Retardation Division, administers the Mental Retardation Family Subsidy Program. Its goal is to enable mentally retarded persons to remain in or return to their homes, avoiding institutional placement. Children under age 18 with a primary diagnosis of mental retardation are eligible. Priority is given to severe and multiple handicaps, degree and need in family environment, and potential for greatest benefit. There is no family income ceiling, however. Aid is in the form of cash subsidies with a \$250 per month limit per family. A team of professionals and the parents is responsible for developing and implementing an individualized service plan for the child. Services paid for include diagnostic assessment, child care, educational and training programs, special diets and clothing and equipment, and medical expenses. \$398,000 was appropriated for FY 1982 and \$525,800 for FY 1983.

Nebraska

The Disabled Persons and Family Support Act, administered by the Department of Welfare, was set up to enable disabled persons to live at home, to promote

independent living and employability, and to promote cost-effective health care alternatives. Eligible recipients are families providing for a disabled member at home (or who could return home under the program) and disabled persons living independently who are or could become employed. Disability is functionally defined, combining the developmental disabilities and vocational rehabilitation definitions. Families must demonstrate that their income (plus insurance, other support services) is insufficient to maintain the disabled person at home. Priority is given to severely and multiply disabled people. Potential for "success" and the cost-effectiveness of this particular care alternative are also considered. Services included are counseling and training programs, transportation, attendant care and homemaker services, health services, and special equipment or architectural modifications. The maximum average monthly payment is \$300 per family during any one-year period. The appropriation for this program, which began January 1, 1982 and terminates July 1, 1986, is \$500,000 per year.

#### North Dakota

The Pilot Family Subsidy Program is administered by the Social Services Board, Community Services Division. Priority is given to developmentally disabled children who are currently institutionalized and who will return to the family home. There is no age limit, however. Eligibility is based on a first-come, first-served schedule with a waiting list. Aid is in the form of cash subsidies with a basic care subsidy of \$15 per week paid monthly plus up to \$35 per week for services such as medical care, counseling, respite and babysitting services, recreation, transportation, special diets, and equipment. \$200,000 was appropriated for this program in FY 1981-1982.

#### Pennsylvania

The Family Resources Services Program is administered at the local level through the county mental health/mental retardation system under the auspices of the state Department of Public Welfare, Office of Mental Retardation. Aid is in the form of services and supplemental payments based on client



needs to enable the family to maintain a mentally retarded child or adult in their home. There are no age limits or financial criteria. Borderline to profoundly retarded individuals are eligible clients. Eligible caretakers include natural and adoptive parents, foster parents, siblings and other legal guardians. Services provided may include in-home therapy, transportation, recreation, respite care, homemaker services, and family education and training. \$3.5 million was appropriated for FY 1981-1982 under a 90% state, 10% local matching formula.

#### Rhode Island

The Department of Mental Health, Retardation, and Hospitals, Division of Retardation, administers the Parent Deinstitutionalization Subsidy Aid Program. Aid is in the form of cash subsidies. Only natural, adoptive or foster parents may apply for the program and clients must be mentally retarded persons who have resided in a state residential facility for over 90 days. There are no age limits or financial criteria. Services provided include basic care and training. Not less than \$25 nor more than \$60 per week is allowed for the basic care of each client, and \$5 - \$15 per week for training. The allowance may be used according to parent discretion. Appropriations for FY 1981 - 1982 totaled \$156,000.

#### Washington

The Home Aid Resources Program, administered by the Department of Social and Health Services, Division of Developmental Disabilities, provides an Individual Program Plan for each family to enable developmentally disabled people to remain in the home or community. No cash subsidies are granted. Priority is given to children. Services provided are respite care (24 day maximum per year), extended care (30 day maximum), parent-to-parent outreach, and resource therapies when not available elsewhere in the community. The focus is on parent training and involvement. Service providers sign a contract with the state and are paid by invoice voucher. \$3 million was appropriated for FY 1979 - 1981.



A SHORT DEFINITION OF AUTISM\*

Autism is a severely incapacitating life-long developmental disability which typically appears during the first three years of life. It occurs in approximately five\*\* out of every 10,000 births and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism.

The symptoms are caused by physical disorders of the brain. They must be documented by history or present on examination. They include:

1 - Disturbances in the rate of appearance of physical, social and language skills.

2 - Abnormal responses to sensations. Any one or a combination of sight, hearing, touch, pain, balance, smell, taste, and the way a child holds his body are affected.

3 - Speech and language are absent or delayed while specific thinking capabilities may be present. Immature rhythms of speech, limited understanding of ideas, and the use of words without attaching the usual meaning to them are common.

4 - Abnormal ways of relating to people, objects and events. Typically, they do not respond appropriately to adults and other children. Objects and toys are not used as normally intended.

Autism occurs by itself or in association with other disorders which affect the function of the brain such as viral infections, metabolic disturbances, and epilepsy.

On IQ testing, approximately 60% have scores below 50, 20% between 50 and 70, and only 20% greater than 70. Most show wide variations of performance on different tests at different times.

Autistic people live a normal life span. Since symptoms change, and some may disappear with age, periodic reevaluations are necessary to respond to changing needs.

The severe form of the syndrome may include the most extreme forms of self-injurious, repetitive, highly unusual and aggressive behaviors. Such behaviors may be persistent and highly resistant to change, often requiring unique management, treatment, or teaching strategies.

Special educational programs using behavioral methods and

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\*Adopted by the Board of Directors of the National Society for Autistic Children, June 27, 1977.

\*\*In 1979, new research data showed the prevalence for those who fit the label of "autistic-like" is approximately 15 in 10,000 - a figure now used by NSAC.

designed for specific individuals have proven most helpful.

Supportive counseling may be helpful for families with autistic members, as it is for families who have members with other severe life-long disabilities. Medication to decrease specific symptoms may help certain autistic people live more satisfactory lives.

Note: This short definition is based on the Definition of the Syndrome of Autism, the official definition adopted by the Board of Directors of the National Society for Autistic Children, 1977. It is a working definition, and will be altered as indicated by the results of ongoing research.

AUTISM

by Lorna Wing, M.D., 1973

British National Society for Autistic Children

The disability is a problem of understanding messages from the senses, especially sight and hearing. Although the eyes and ears of autistic children seem normal, when messages from them reach the brain they are not linked into an understandable picture of the outside world, it is believed, leading to a lack of understanding of speech and gesture and hence a lack of ability to communicate. Because of this, autistic children appear to be withdrawn and seem to live in an isolated world of their own. Moreover, due to the frustration caused by the inability to communicate, there is often disturbed behavior.

Prevalence is about 4 in 10,000 school age children which makes about 3,000 in England and Wales.\* Boys are affected more often than girls in a ratio of about 3 to 1. About one third have associated gross neurological abnormalities. Most siblings are normal but cases are known of two autistic children in one family, sometimes identical twins. The children may be abnormal from birth or they may become autistic after anything up to three years of apparently normal development. The causes of autism are not known, but a commonly held view is that the development of some parts of the brain is very severely delayed. Autism was first diagnosed 30 years ago. Before then - and sometimes now - autistic children were thought to be incapable of learning. Many adults now in mental subnormality hospitals are cases of undiagnosed early childhood autism.

Autistic children do in fact have severe learning problems, but if taught in the right way, they can benefit from teaching. Even the most handicapped are able to learn some socially acceptable behavior, and some are capable of far more than this. When testable, the I.Q.'s of autistic children vary greatly from the above average to severely sub-normal.

Autistic children look normal and healthy (providing that they have no associated handicaps such as spasticity) but their language and social development is likely to be several years behind their physical age. However, their skills with tasks which do not need language may be at their age level or better. Most workers who have followed up these children have agreed that they do best if they are able to attend school and receive specialized education. Under these circumstances many of them will, it is hoped, be able to find employment as adults. The majority will need sheltered work but some will be able to find open employment in a suitable occupation with a sympathetic employer.

The range of work in which autistic adolescents have been placed is remarkably wide. The British National Society for Autistic Children knows, for example, of 2 at University studying mathematics, 1 who is a Fellow of the Royal College of Organists, 3 in offices (after passing some "O" levels), 3 piano tuners, 1 brick-layer and 1 street cleaner. All of these young people are able to live at home.

The level of occupation depends upon each adolescent's special skills, and how badly he is handicapped. The latter can vary from the very severe to the very mild. However, although each person must be considered as an individual,

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\*80,000 in U.S.



they do have certain problems in common, which affect their employability. These can be listed as follows:

1. Their inability to understand and use language except on a simple concrete level prevents them from doing jobs which involve more than the minimum amount of talking or reading.
2. They have difficulty in understanding complex instructions. Given time they can learn rules or routine procedures and once learned they will carry them out exactly. They are not able to manage if procedures change frequently or if many decisions have to be made.
3. They cannot do work that needs imagination, although they may be quite inventive in mechanical or electrical trades.
4. They are often unable to find things out by asking questions. Therefore, when they start work they need someone to take a special interest, to show them the cloakroom, how to obtain a meal in the canteen, what time to finish work, etc.
5. Some of them are very sensitive to loud noises and bright lights, and this may effect employment.
6. Most autistic adolescents who are considered for work tend to be gentle, placid and even tempered. However, if a complicated situation arises in which routine is upset and swift action is needed they may become extremely confused, agitated and perhaps irritable.
7. They may appear to be withdrawn, but they are in fact very sensitive to other peoples' attitudes. In particular they can be easily upset if people become impatient and do not give clear directions.
8. A complicated journey to work may present a problem. The route will be followed if all goes according to plan, but an unexpected delay or change in the services might cause confusion and distress.

The above list stresses the difficulties. It is only fair to add that when they settle into employment, autistic adolescents and adults are reliable, conscientious and extremely hard-working employees. They are scrupulously honest and incapable of lies or deceit (which sometimes is a disadvantage in certain social situations). Once other people become used to their handicaps, autistic adolescents and adults are almost always well-liked, and usually receive sympathetic consideration from their colleagues.



# AUTISM SERVICES CENTER

Training, Consultation, Advocacy, Information

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304-523-8266

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September 28, 1981

Dear Director:

Autism Services Center, under a contract with the West Virginia Department of Health, is directing a project to write a state plan for autism, entitled "Opening Doors for West Virginians with Autism."

We are in the process of gathering information about existing services in our state for this severely handicapped population. Your agency or facility is one which might offer such services. Would you please help us by responding to the enclosed questionnaire?

We need to have your reply by October 14, 1981. If you prefer, you may call us at 523-8269 or 525-8014.

Thank you for your time and effort.

Sincerely,

Ruth C. Sullivan

RCS/bkm

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Director, Star?  
Tulsa, Oklahoma

November 2, 1981

Dear Director:

Early in October, we mailed you a questionnaire about your services to the autistic population in this state. We have not heard from you and several other agencies/institutions. Would you please take a few moments and fill out the questionnaire so that we have a more accurate survey for our State Plan "Opening Doors for West Virginians with Autism." It is essential that all regions are represented.

We need to have your reply by November 14, 1981. Please get it in the mail soon.

Thank you for your time and effort.

Sincerely,

*Barbara K. Mabey*

Barbara K. Mabey  
Assistant to the Director

# AUTISM SERVICES CENTER

Training, Consultation, Advocacy, Information

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101 Richmond Street  
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304-623-8288

Ruth Christ Sullivan, Director

March 22, 1982

Dear

Thank you for responding to our questionnaire "Opening Doors for West Virginians with Autism" - Survey on Existing Services in WV for Autistic People.

We have read your response with interest. We would like to follow up on two questions, question 7 and 8, to further determine with greater accuracy what services are available for autistic clients in our state.

In regard to question #7, asking if you have a specific program for autistic persons, you, along with the other 52 responders, replied "No." Your response to #8, "Do the autistic people come to your institution/agency for service? How often? Daily? Weekly? Monthly?", indicates that your clients come to you on a regular basis. Would you please describe the kind of program you offer for autistic or autistic-like clients served by your agency.

It would be helpful to us if you could describe what they do. For example: counselling, social skills, academics, self help (please give example), community living skills (e.g., riding on public transportation).

Thank you for taking more time for our autism project. Please respond at your earliest convenience.

Sincerely,

*Barbara K. Mabee*

Barbara K. Mabee  
Assistant to the Project Director

"Opening Doors for West Virginians with Autism"

Survey on Existing Services in WV for Autistic People

QUESTIONNAIRE

Name of facility

Street

City

County

State

Zip Code

Telephone

Name of person filling out questionnaire

Position

Date

Office telephone number

Funding: Please check

☐ Public

☐ Private  
Please describe

Appendix 3.  
page 4.



QUESTIONS FOR SURVEY ON EXISTING SERVICES IN WV FOR AUTISTIC PEOPLE

1. Do you currently serve autistic or autistic-like people in your agency/institution?
2. If none now, have you had any before?
3. How many have you identified?
4. How many have been formally diagnosed? By whom?
5. How are autistic clients referred to you?
6. Where do you refer them if you cannot serve them?
7. Do you have a specific program for autistic persons? What kind of program? (e.g., education, psychotherapy, group home)
8. Do the autistic people come to your institution/agency for service? How often? Daily? Weekly? Monthly?

Appendix 3.  
page 5.

2

Appendix 3.  
page 6.

- 140

## AUTISM SERVICE QUESTIONS

15. Is the severity of the disability a criterion for admission or discharge?
16. Are there age limits for admission and discharge?
17. How are services to clients paid for?
18. Is your agency/institution interested in serving autistic citizens as a matter of policy? (even if you do not now serve them)
19. If so, what additional resources or support would you need to serve them? (e.g., more trained staff, more space)
20. Do you consider your institution/agency an appropriate placement for an autistic person?

Appendix 3.  
page 7.

RESOLUTION

The West Virginia Chapter of the National Society for Autistic Children endorses the plan for the establishment of an Autism Center in Huntington, West Virginia. The need for a facility to diagnose, treat and educate persons with severe behavior and communication disorders, such as autistic and autistic-like, has long been recognized, especially in the tri-state area. In addition to helping developmentally disabled people, a center which will work with both parents and educators will be a significant contribution of the well-being of autistic people. We, the West Virginia Chapter, enthusiastically support and recommend the consideration of this facility in the planning of health, education and residential programs for the developmentally disabled population of the State of West Virginia and the surrounding areas.

Eugene Misch, President  
West Virginia Chapter, National Society for  
Autistic Children  
April 21, 1980





**WEST VIRGINIA CHAPTER**  
of the  
**NATIONAL SOCIETY FOR AUTISTIC CHILDREN**

P.O. BOX 8152

SOUTH CHARLESTON, WV 25303

Resolution  
on  
Education of Autistic and Autistic-like Children

Adopted  
Sunday, November 15, 1981

WHEREAS parents, as lifelong advocates, have the primary, enduring and unending responsibility for the appropriate education of their autistic children, they must carefully monitor and take an active part in all aspects of their educational programs.

WHEREAS, because autism is not only a low-incidence handicap, but is in addition a newly defined and still poorly understood disorder for which research is just now getting underway, parents need a strong commitment to give leadership to all aspects of their children's educational programs.

WHEREAS, parents having learned about autism by living in the laboratory, have, at national, state and local levels, been and are the prime movers of new advances in legislation, new research, new service programs, new standards, new attitudes and new horizons in the autism field, they are natural pathfinders and pioneers for guiding professional development.

WE HEREBY RESOLVE, that we will work for and expect only the highest standards of current professional practice, based on an interdisciplinary approach,

TO WIT: Trainers of teachers and other education personnel who work with our children must have professional qualifications, including appropriate education, training

2.

and recent hands-on experience with autistic persons, and be recognized by legitimate autism professionals as having proper credentials.

Parents must always be alert to the lure of less expensive but quick and administratively expedient solutions, like respite and custodial care in place of appropriate educational programs.

Since specific technology for successful teaching of autistic children is now known, acceptable, recommended and available, we must be vigilant in the oversight of teacher (and other professional) training programs.

We must be particularly careful of our endorsement of accreditation standards.